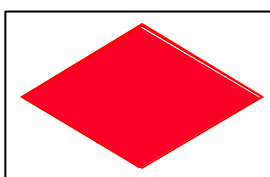


Strengthening Every Family
Forum on supporting parents who have learning
difficulties

**Proceedings of the Strengthening Every
Family Forum**

**Hosted by the Office of the Public
Advocate and the Victorian Parenting
Centre**

**The Hotel Y, Melbourne
9th July 2003**



**OFFICE OF THE
PUBLIC ADVOCATE**



Strengthening Every Family

Forum on supporting parents who have learning difficulties

Contents

Aims and objectives of the forum.....3

Forum program.....5

Keynote speakers

- Prof. Gwynnyth Llewellyn, Sesquicentenary Professor of Occupation and Leisure, University of Sydney.....7
- Dr Dorothy Scott, OAM, Professor, Department of Social Work, University of Melbourne.....22
- Dr David Sykes, Manager, Policy and Education, The Office of the Public Advocate....35
- Mr Warren Cann, Director, The Victorian Parenting Centre.....68

Summary of themes, actions and tasks from concurrent panel sessions and workshops...87



Strengthening Every Family

Forum on supporting parents who have learning difficulties

MELBOURNE – 9 JULY 2003

**Cato Conference Centre, the Hotel Y, 489 Elizabeth Street,
Melbourne**

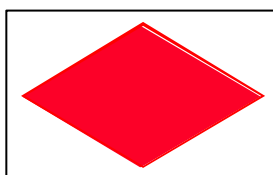
Purpose of the Forum

The Forum brought together key individuals and agencies to explore the range of issues facing parents with special learning needs, their children and their support networks.

Aim of the Forum

The aim of the Forum was to facilitate the development of an action plan for statewide and regional groups to more effectively address the needs of this group. The forum specifically sought to address these issues through focusing on essentially three broad themes:

1. Societal attitudes, perceptions and responses to disability, parenting and social disadvantage.
2. Key features of the current supports and service system that either promote or inhibit effective responses to families where the parent may have an intellectual disability.
3. The extent that current practice reflects best practice in the delivery of parent support and skill development programs to these families.



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Forum on supporting parents who have learning difficulties

Key Objectives of the Forum

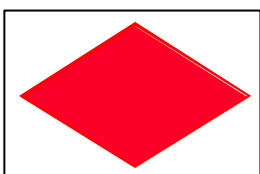
In pursuing these three themes the forum had five key objectives:

1. To identify the critical issues facing parents with special learning needs.
2. To identify service gaps and other barriers that constrain parents with special learning needs in developing their desired role as parents.
3. To explore the promotion and application of the rights framework, as it relates to both children and parents, in support of these families.
4. To identify strategies that will lead to a more effective and informed support system for these families at a statewide, regional and local level.
5. To develop working groups to bring about the strategies proposed.

Key intended outcomes of the Forum

The key outcomes of the forum were:

1. Effective participation in the deliberations of the forum from key stakeholders at statewide, regional and local levels.
2. Publication of the proceedings of the forum that will inform the further development of strategies at all levels.
3. Identification and documentation of strategic action plans focusing on each of the three forum themes.
4. Identification and documentation of the tasks required to achieve actions and the groups or individuals responsible for this.
5. Development of an ongoing partnership between key stakeholders in the development and implementation of the action plans and associated tasks.



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Strengthening Every Family

Forum on supporting parents who have learning difficulties

**Venue: Cato Conference Centre, the Hotel Y, 489 Elizabeth Street,
Melbourne.**

PROGRAM

9.30am **Tea and coffee available on arrival**

10.00am **OPENING SESSION**

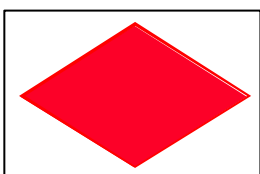
Welcome Address: Julian Gardner, Public Advocate.

Presentation: *Strengthening every family* video presentation

10.40am **KEYNOTE SESSION - A focus on the societal, service system and professional outcomes for parents with a special learning need**

- Prof. Gwynnyth Llewellyn, Sesquicentenary Professor of Occupation and Leisure, University of Sydney
- Dr Dorothy Scott, OAM, Professor, Department of Social Work, University of Melbourne
- Dr David Sykes, Manager, Policy and Education, The Office of the Public Advocate
- Mr Warren Cann, Director, The Victorian Parenting Centre

12.45pm **Lunch will be provided at the venue**



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Strengthening Every Family

Forum on supporting parents who have learning difficulties

1.30pm CONCURRENT PANEL SESSIONS

Panel Session 1

Theme: *Where are we at?*

An exploration of societal attitudes, perceptions and responses to disability, parenting and social disadvantage.

Facilitator: Kris Honey

Members:

Dr David Sykes

Prof Gwynnyth Llewellyn

Fr Nic Frances

Panel Session 2

Theme: *What are we*

doing? Identification of the key features of the current service system that promote or inhibit an effective response to families where parents have a special learning need.

Facilitator: Jan Matthews

Members:

Dr Karen Nankervis

Dr Dorothy Scott

Ms Brenda Boland

Panel Session 3

Theme: *How are we*

doing it? Exploration of the extent to which our current practice reflects best practice in the delivery of parent education programs to parents with a special learning need.

Facilitator: Alan Hudson

Members:

Ms Robyn Mildon

Ms Constance Jenkin

Dr Rosemary Sheehan

2.45pm CONCURRENT WORKSHOP SESSIONS

Responding to the issues of the day and the development of action plans.

All delegates will be assigned to one of 6 workshops.

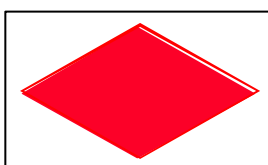
3.30pm Afternoon Tea

4.00pm FINAL PLENARY SESSION

Reporting back from Workshop Sessions

Closing Address: Prof. Alan Hudson, Head of Dept of Psychology and Disability Studies, RMIT University.

5.00pm Close of Forum.



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Parents with special learning needs

Professor Gwynnyth Llewellyn

Sesquicentenary Professor of Occupation and Leisure Sciences

University of Sydney

To start I would like to thank the Victorian Parenting Centre and the Office of the Public Advocate for supporting me to be here today. I am particularly pleased that this wonderful initiative is Victorian: I am known for saying the Victorians are way ahead than New South Wales in thinking about, caring about and worrying about creating as successful as possible outcomes for families headed by parents with special learning needs.

My task this morning is to cover three critical questions. The first is *where have we come from?* This makes us think about what, if any, progress we have made as a society and in our support systems, and as practitioners working towards more effectively responding to parents with a disability and their families. The second question is *how are we doing now?* In other words, how well are we doing now as a welfare system in supporting these families. And the third and last question is *where to from here?* For this question I have been asked to provide my view on what I see as the key strategic directions for the future. Implicit in this is an assumption that we could, and indeed need, to do better. And, this task is to be done in 30 minutes – a race against time!

I have resisted the temptation to provide an overview of what we now know about people with intellectual disability as parents – and what we still need to learn – and instead have decided to present only relatively few examples in some depth to stimulate discussion. For a review of current research and practice points in working with parents with special learning needs I invite you to check out our new website on www.fhs.usyd.edu.au/sols/fssp/. Other websites are included in the reference list.

Parents with special learning needs have always been with us – in every society, at every time. There is nothing new or unusual about people having difficulty learning, or cognitive

limitations, or intellectual disability or mental retardation or intellectual handicap or learning difficulties or whatever other term we use. Having a special learning need and having difficulty grasping the more abstract concepts in our world is simply the other end of the spectrum from those who learn very quickly and can think abstractly –whether this be about pure mathematics, astronomy or quantum physics. Human ability to learn and think abstractly comes on a continuum – from those very able to those much less able on this one dimension of humanness. What is different across cultures and time is the way we think about people who have difficulty learning – our attitudes and behaviours that, as it were, ‘assign’ people with intellectual disability to a particular position in our community.

This theme – the social context of parenting with a disability or special learning needs runs through my presentations today. It is about paying much more attention to the social context of the families that we are endeavouring to help – the parents and the children - and moving away from such intense focus on their learning disability or learning needs.

So to begin: Where have we come from?

Late last year the American Association on Mental Retardation published a book titled *The Best of AAMR. Families and Mental Retardation: A collection of notable AAMR Journal Articles across the 20th Century* (Blacher & Baker, 2002). I recommend this book as it provides some useful insights into research, policy and practice in relation to families and intellectual disability over the last century. The percentage of papers on parents who have mental retardation – to use the North American term – is relatively small, four out of the 32 selected. Of these the earliest was published in 1947 and authored by Phyllis Mickelson, a social worker from Minnesota. This paper is titled *the feebleminded parent: A study of 90 family cases*.

The 90 cases (which totalled 105 parents) included both men and women who were feebleminded; at the extremes, one person had an IQ in the range 30-39 while two others had IQ's over 75; most however had IQ's from 40 through to 70 with a mean of 58.6. Mickelson used a rather simple but effective way to group the parents on adequacy of care based on, and here I quote, “absence or presence of social evidence which is customarily accepted as indicative of child neglect” (p. 226). Thus there were three groups of parents as follows:

- **Satisfactory care:** not only the absence of complaints from the community but positive evidence that the children were kept clean, adequately fed, clothed and supervised, and regular in school attendance. There were 38 or 42% of families in this group.
- **Questionable care:** some inconsistency or inadequacy of care but not sufficient degree to justify removal of the children as neglected. There were 29 or 32% of families in this group.
- **Unsatisfactory care:** evidence that the children had been removed as neglected (there were ten such cases) or that their care was sufficiently poor to justify consideration of such action. There were 23 or 26% of families in this group.

Mickelson's conclusions sum up her findings and also her approach. She asks, and I quote: "What have we learned? In the first place, that the care these parents gave their children varied all the way from Satisfactory to Questionable to Unsatisfactory, with somewhat less than half, it is true, having given satisfactory care, but with only one-fourth having given unsatisfactory care. *Thus the parents' mental status did not appear to be sole determinant of adequacy of childcare; otherwise all of the children would have been neglected* (emphasis added). We therefore searched for other factors. Ten were considered. Of these five seemed most important: namely, the mental health of the parents especially that of the mother; the degree of harmony between husband and wife; the number of pregnancies and the number of children in the home; and finally the adequacy of income. We had to analyze each of the factors separately; somewhat belatedly we call attention to one of their most important characteristics: their interrelatedness" (Mickelson, 1947 cited in Baker and Blacher, 2002, pp.232-233).

Fifty-six years later similar answers are found in any study of parents with learning difficulties – that a significant proportion of parents with intellectual disability provide satisfactory care – usually around one half; with only around one-quarter giving unsatisfactory care and the others somewhere in between. The factors influencing each end of the spectrum – satisfactory and unsatisfactory care - remain much the same. *IQ is not one of these*; rather it is the inter-relatedness of several factors that determine whether families headed by parents with intellectual disability does well or otherwise. These factors are: health status particularly of the mother; marital (or other) relationships;

number of children in the family home; and financial resources. We would now add the influence of the parent's own upbringing on the way they carry out their parenting, parental self-esteem and the temperament and behavioural characteristics of their child/children (McGaw, Ball & Clark, 2002; Tymchuk & Keltner, 1991).

These consistent findings over more than half a century ought to give us pause for thought. Where do we currently put our support efforts: is it into ensuring good physical and mental health for mothers with intellectual disability? Do we focus on supporting parents to develop healthy, stable and supportive relationships? Do we assist parents to plan appropriately for the number of children in their families? Do we work towards ensuring that families have adequate incomes to meet their family responsibilities? In other words do we focus our efforts on the context – family, social and environmental – in which parenting takes place – or do we focus more of our attention on the individual parent and their behaviours, attitudes, skills and so on.

There is another early paper included in the same publication that also provokes reflection on our current practices. This paper by Harold Skeels and Harold Dye was published even earlier – in 1939. This paper is the first to demonstrate that stimulation can change intellectual ability in young children. This paper is about giving children a head start – before such notions became embedded in policy, practice and research mantras across the globe. Thirteen young children classified as dull normal living in orphanage care were subjected to an experiment. A control group of children continued living in the orphanage with no intervention.

What did Skeels and Dye (1939) find? I quote: “Mean IQ at time of transfer (to experimental conditions) was 64.3 with a median at 65. The average gain in intelligence quotient during the course of the experiment was 27.5 points with a median of 23. The mean IQ on the “last” tests was 91.8 with a median at 93. Every child showed a gain, the range being from 7 points to 58 points. Three children made gains of 45 points or more, and all but two children gained more than 15 points” (Skeels and Dye, 1939, cited in Blacher and Baker, 2002, p. 27).

You are possibly wondering what does this significant gain in intellectual ability have to do with parents with special learning needs? The relevance is the *experimental condition* – the intervention that had such a dramatic effect on the children. The intervention was this: the children in the experimental group were transferred to wards in an institution for the feeble-minded which housed ‘girls’ ranging in ages from eighteen to fifty years and with mental ages ranging from five to twelve years. In other words these children spent an average of around 19 months living in a different environment with mentally retarded, feeble minded and dull normal women – and the children thrived. The ‘feeble minded’ women, as the authors report, took a great deal of interest in the children, playing with them, making clothes for them, spending their small allowances on special gifts for them and so on. As I mentioned this is one of the earliest studies of the effectiveness of early intervention. What has been forgotten is that women with intellectual disability carried out this intervention.

This finding that mentally retarded, feeble-minded and dull normal women effectively cared for and stimulated these young children brings us back again to the importance of social context. The women were caring for these children in a situation devoid - we could hypothesize - of many of the pressures – social, financial, informational, and relational – that exist in the wider community. Does this suggest that most of the difficulties experienced by parents with intellectual disability relate not to their intellectual impairment per se but rather to the pressures of their socio-economic- cultural community, their life situation, past and present? The findings from Skeels and Dye’s study also raise another interesting question. Is it that caring for and stimulating children is much easier when women can learn together, share the parenting, and have opportunities to watch and learn from others?

I am of course not suggesting here that we should isolate women with intellectual disability, put them on wards, and then expect them to mother their children. I am suggesting however that these two early papers contain important findings as relevant today as these were back in the 1930’s and 1940’s. The first paper demonstrates that IQ is not the determinant of parenting success that we often regard it - rather social factors are critically important. The second paper reminds us of the importance of social context –

not only as a potential support or barrier to effective parenting – but as a context in which effective modelling and learning about parenting can take place.

How are we doing?

The second question I have been asked to address today is how are we doing? This is a tough one to answer without an evaluative context – in other words, against what standard? If we asked, for example, how are we doing against other countries with similar social welfare systems, then the answer is pretty much the same – for example, in relation to the UK, Canada, Scandinavia and New Zealand. The US is a somewhat different case given their vastly different welfare and health systems and also the marked differences found in programs from state to state. In brief, in the US service eligibility is related to disability and provided along categorical lines – for example, for mental retardation, cerebral palsy and so on. When parents have significant learning needs but are not classified as disabled they are not eligible for these services – they are left to the mercy of the social security system primarily directed at achieving higher employment levels rather than addressing their parenting needs. Tymchuk, Lakin and Luckasson (2001) in a recent useful publication refer to the latter group as the forgotten generation – these are people with mild cognitive limitations rarely supported by current policies and practices.

There are essentially three strands in the research literature. These align reasonably well with policy and practice over the last twenty or so years in Australia. These strands form a useful framework for considering how well we are doing. The first strand focuses most directly on the individual's cognitive limitations. This strand began with questions about whether people with intellectual disability *could be adequate parents*, as we saw in Mickelson's early article, and later, around the 1980's, turned attention to the question could people with intellectual disability *be taught* to be adequate parents. This change in direction came about with the emphasis on instructional technologies in the field of intellectual disability: applied behavioural methods, task analysis, and later contextual and situational learning approaches as ways to teach people with intellectual disability. There is now substantial evidence, using a variety of empirical methods including randomised controlled trials, demonstrating that parents with intellectual disability can and do learn, retain the knowledge taught, and apply this knowledge appropriately. There is also good evidence about how learning can be enhanced, with the principles for effective teaching and learning well documented (see for example, Bakken et al., 1993; Feldman, 1994;

Llewellyn et al., 2002, Tymchuk & Feldman, 1991). Much of this research evidence on how to teach parents with intellectual disability has found its way into disability and family support practices in Australia.

The second strand in the research literature is concerned to know more about the reality of peoples' lives where their voices have been 'silenced' such as is the case with women - and men - with intellectual disability (see for example, Traustadottir and Johnson, 2000). There are studies reported from around 1990 onwards which use narrative methods to understand parents and their family lives, and in some instances, also their children's lives (e.g., Booth & Booth, 1994; 1998; Llewellyn, 1995, 1997; and more recently, Perkins et al., 2002). This strand focuses attention on what is, not what ought to be. Narrative research is not concerned with whether what is, is good enough, but rather focuses instead on parents' perspectives rather than seeing their lives through the eyes of others. There are examples of good practice in working with parents with intellectual disability in this country that reflect this approach. This is when workers base their work with parents and families on where the family is at, what the family wishes to achieve, and then set out to help the family achieve their family goals. This approach – often called the strengths-based approach - also recognises the inherent limitations in imposing the professional viewpoint upon families – in terms of what parents should or should not do. A good example of this in relation to assessing parenting capacity can be found in Margaret Spencer's article *Proceed with Caution: The Limitations of Current Parenting Capacity Assessments*, found in the 2001 Winter edition of the NSW-based journal, *Developing Practice*.

The third strand although not as well developed as the first two focuses attention on understanding parenting as a contextual, rather than an individual activity. Parenting in this approach is viewed as a dynamic, context-dependent state. Here parenting is thought about as a three-way interaction – between parental knowledge/skills, the complexity of the task/s, and the environmental context (including others who participate in parenting). Studies in this tradition focus more on the socio-environmental context in which parenting occurs including the availability and effectiveness of social supports and the relationship between social support and other areas of parenting rather than the individual parent's parenting ability or capacity (see for example, Llewellyn and McConnell, 2002). There are

significant barriers to taking this dynamic, context-dependent state view of parenting forward. I will return to these barriers a little later.

There is one significant area of practice with parents with intellectual disability that is virtually missing from the literature yet is a reality of everyday practice in this country and elsewhere. This is the frequency with which parents with intellectual disability are involved in child protection proceedings. This is another part of the social context surrounding parents with special learning needs. It is true that there has been, and particularly in the US, quite a lot of attention by legal scholars to the discriminatory treatment received by these parents – seemingly based on prejudicial beliefs stemming from out-dated stereotypes invoking images of increased fecundity among women with intellectual disability leading to protectionist and isolationist views based on eugenic beliefs.

Until recently however there had been little attention given to the processes and activities occurring in care and protection proceedings nor the outcomes of these processes. This is interesting given as we saw at the beginning of this presentation that even the earliest reported studies were concerned about whether parents could provide non-neglectful care. Not until Taylor et al's. study undertaken in Boston and reported in 1999 was there any population-based (in contrast to case study) empirical evidence that parents with intellectual disability were not only over-represented in care and protection proceedings but that they were also subject to differential findings – inconsistent with their abilities or parenting practices. Now there is evidence from this country as well as others that this is indeed the case (Goodinge, 2000; McConnell, Llewellyn & Ferronato, 2000). Put simply, parents with intellectual disability and their children suffer harsher outcomes than other parents in care and protection proceedings. These outcomes are not driven primarily by parents' inability to be adequate parents. Rather they are driven by: firstly, continuing outmoded views about the unlikelihood of their being adequate parents; secondly, by thinking which continues to (falsely) equate intelligence quotient with parenting ability; and, thirdly by systemic imperatives – in particular, the lack of available and appropriate resources to support these parents and their families (Goodinge, 2000; McConnell & Llewellyn, 2000; McConnell et al., 2000).

Where to from here?

Now to the last question. Where to from here? I want to take us back to Mickelson's early study. In essence, she found and studies since have consistently confirmed, that it is not the person's intellectual disability that is the problem! The big question is: are we ready to accept that social context is the major contributing factor to the difficulties experienced by parents with intellectual disability?

I trust that we would all agree, whether in 1947 or 2003, that disability is not a neutral concept. It is value-laden and socially constructed. We are gradually coming out of an era that locates any 'disability problem' within the individual. In this model of disability whatever arises is a consequence of individual physiology, biology, neurology and even moral status, motivation, effort and so on. While often disparagingly referred to as the medical model – it is really an individual model focusing attention on the person as the problem.

Slowly there is growing acceptance that disability is not an individual problem. Rather disability is about the way we regard people – this is what en-ables or dis-ables them. This thinking is based on the social relational model of disability, which speaks to the effects of prejudice and discrimination. Social factors create barriers, deny opportunities, isolate and devalue, and in consequence, dis-able people. The new International Classification of Functioning, Disability and Health (ICF) incorporates this social model thinking. This classification system uses the notion of performance to record what a person can do in their current environment. It also recognises the notion of capacity. That is, what a person could do – what is possible – in an environment with the disabling barriers removed. This social context model does not deny the reality of impairment; what this model does is focus attention on the disablism caused by society – the way in which people with impairments are regarded as abnormal, atypical and therefore excluded.

Disablism can be seen for example in the fact that people with an intellectual disability are more likely to be found in the most socio-economically disadvantaged groups. There are also more people with an intellectual disability in groups already socially disadvantaged. People with intellectual disability are also more likely to have experiences that trigger their involvement with assessment, intervention and monitoring systems. This is not typical of

others without a disability. So for example at school they are much more likely to be excluded from learning with their age peers; as parents they are much less likely to be accepted into the local neighbourhood play group or babysitting club – social exclusion in its widest sense.

Another way to understand disablism is to realise that to receive ordinary entitlements that others receive as a matter of course, people with intellectual disability have no choice but to be assessed. Assessment has become the route to ordinary entitlements for people with an intellectual disability (and other disabilities). As children, they are assessed to access schooling; as young people, they are assessed for employability or day programs; as adults they are assessed for housing, for disability support; as parents – they are assessed for family support and assessed and assessed – the list goes on. These assessment routines are not experiences shared by people who do not have impairments. These few examples help illustrate the disabling practices in the social context surrounding parents with special learning needs.

In contrast, there is a raft of programs at federal and state levels in this country trying to provide family friendly communities and strengthen families. In mission statements, policy documents and service agreements there is much talk of supporting families. This means investigating social factors, which make life difficult for parents and families, and trying to ameliorate some of these conditions. There are many ways in which our society is endeavouring to support non-disabled parents: parent-friendly workplaces; alternative child caring arrangements in family day care, long day care; home visiting, playgroups, parent education and many more. Another big question is: are we paying the same attention to the social context for parents with intellectual disability? Are we recognising the socio-cultural-economic environments in which they are carrying out their parenting? Are we recognising and addressing the significant barriers and the disablism they experience? Crucial to the efforts to support other parents in the community is the understanding that if parents are well supported, there is a greater likelihood that children's welfare can be maintained, developed and enhanced. Do we apply this same assumption to our systems and practices with parents with intellectual disability?

In conclusion, we no longer need to ask can parents with intellectual disability be adequate parents or be taught to be adequate parents. We are starting to understand something about others in their lives, and their social relationships and connectedness or otherwise with their community – in all of this we are also learning from parents themselves something of the disability that they have experienced. We understand now that parenting is not just a function of what a mother or father does. We understand that parenting is a function of social environment, of the support parents receive, access to resources, and the opportunities parents have to learn how to be parents. This of course is true for all parents. The challenge is to turn this knowledge about the critical influence of social context – on both disability and on parenting – into action to support parents with special learning needs.

To take seriously and attempt to redress the disadvantages inherent in our society in having an impairment – and in particular being a parent with a special learning need– we have quite a way to go. As a way to conclude this presentation I invite you to imagine the following hypothetical situation. From this day on and right around Australia that all information and services aimed at parents and families routinely includes parents with intellectual disability as an expectation. At the same time all information and services aimed at intellectually disabled people routinely covers parenting and family matters as the expected case – that they too may already be, or wish to become parents. This would move us a significant way forward to including people with intellectual disability as citizens able to enjoy the benefits of our society. This is only way one we could go forward. I look forward to being part of the deliberations this afternoon as you initiate other ways to move Victoria even further forward in this critical area of families headed by parents with special learning needs.

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Confronting the Issues of Supporting Parents with a Disability

Associate Professor Dorothy Scott, OAM

Introduction

I have been asked today to speak from a child protection perspective. Those who work in the child protection system on a day-to-day basis are probably in a much better position to do so. I have had some limited practice experience with parents with an intellectual disability within the child protection system, including working on my sabbatical leave in an intensive, home based service. I have much greater experience working with parents with a serious mental illness for whom I helped pioneer a number of innovative inpatient and outpatient services in this State 20 years ago, and while the needs of these two groups of parents are quite different, and the diversity within each group can be as great as the diversity between any parents in the community, from the perspective of the child protection service, the fundamental questions are the same:

- How do we work across the interface of two sectors, one which has a primary focus on the child and one which has a primary focus on the adult?
- Under what conditions is family-centred policy and practice possible?

The logo of the Adelaide Women's and Children's Hospital with the gestalt of mother and infant, symbolizes the challenge. Most people looking at this gestalt can see the mother and most can see the child but very few can see them both at the same time. Even fewer people seem able to see the father. If you look hard enough you can see him but you have to really want to find him! The same is true for the extended family and social network - what we call family-centred practice is typically mother-centred practice, whereas an ecological framework of child-in family-in kith and kin networks- in community is required.

The differences between those who see the child and those who see the parent are sometimes subtle and the blinkers of those on the other side always seem obvious while our own blinkers remain invisible to us.

For example, the title of today **“Confronting the Issues of Supporting Parents with a Disability”** strikes those from a child welfare perspective as incomplete. We would prefer to say **“Confronting the Issues of Supporting Parents with a Disability and their Children”**, for while it is true that “children need all the support their parents can get! ” supporting parents and supporting children may require different but hopefully complementary strategies.

Like in an inter-tribal conflict, we tend to tell atrocity stories about each other and to be quick to feel that our side is being disadvantaged. For example, when I was preparing this paper I searched the website of the Department of Human Services for the Protocol between disability services and child protection services which I recall being instituted in 1993 after the deaths of several children but I could not find it under Disability Services. I found a Protocol between IDS and Psychiatric Services, a Protocol between the Office of Corrections and Disability Services, a Protocol between Disability Services and Juvenile Justice and a Protocol with Police. There were three documents on supporting parents with an intellectual disability which was good to see but alas, no protocol between Disability Services and Child Protective Services. Do I choose to see this as evidence of how adult focused services tend to ignore the needs of vulnerable children of their clients?

Eventually, after ringing the Department, I was able to find it hidden in an obscure place in the Child Protection area- Community Care, then Manuals, then Child Protection, then Practice Guidelines, then Protecting Children volume 2, and there it was – a 10 year old Protocol between Child Protection and Intellectual Disability without any apparent update in the last decade, despite considerable advances in our knowledge in that time on the vulnerability of infants and young children. Perhaps the children of parents with an intellectual disability are a low priority for both disability services and child protection.

This is not so in the field of mental health where we are witnessing considerable attention and some very creative policies and practices on the needs of children of parents with a serious mental illness, and where the voices of the children and young people themselves are heard in forums such as this. Why this is not so in relation to intellectual disability, I am not sure quite sure.

Historical Perspective

From a child welfare point of view, the issues relating to parents with an intellectual disability are not new. The only known intact set of historical case records of a child protection agency in Australia, and possibly in the world, are those of the Victorian Society for the Prevention of Cruelty to Children, now called the Children's Protection Society. In researching these records for our recent book published by Melbourne University Press entitled *Confronting Cruelty, Historical Perspectives on Child Protection in Australia*, Dr Shurlee Swain and I analysed a representative sample of case histories dating back to the 1890s. Unfortunately the terminology used did not allow a numerical differentiation between parents with an intellectual disability and those with a psychiatric disability, but suffice to say that both groups of parents regularly appeared in the case files across the century.

Until the 1970s there were few services for any parents which aimed at preventing the admission of children into care, or which assisted families to be reunited once they were admitted, and adoption was seen as a panacea for the children of unmarried mothers, women with a mental illness and women with an intellectual disability.

With the deinstitutionalisation of child welfare in the 1970s came a range of programs aimed at placement prevention and family reunification. By the late 1980s in Victoria the legislation in this State caught up with the policy shift, which had occurred over the preceding two decades. While planning for the stability in the child's life was meant to be a guiding principle, what has dominated is the principle of the "least restrictive" option, enshrined to a more extreme degree in this State than elsewhere in Australia or the rest of the western world. Statutory orders have become very short term and from the large scale warehousing of children in institutions in the 1960s, the pendulum has swung to create a system in the 1990s which is now widely recognised as failing to provide stability and security for that relatively small group of children who are unable to return to the care of their parents.

Other jurisdictions have been more successful in creating a legislative framework which emphasizes diversion, placement prevention and reunification, while at the same time

ensuring that where this has failed, serious and timely consideration is given to securing stable substitute care for the child, preferably within their extended family but if not in an adoptive or permanent foster family where there is opportunity for the child to have continuing contact with their natural family.

Child Protection Data on Children of Parents with an Intellectual Disability

The available child protection data on any sub-group of parents is limited and comes from two very different sources. One is Child Death Inquiries and the other is CASIS, the database of the child protection system. The former provides an in-depth analysis of a small and skewed sub-group of cases, totalling 32 in 2002. The latter gives broad statistical profiles but little insight into case processes.

I shall examine the implications of each in turn. In the past inquiries into the deaths of children known to the child protection system were published as anonymous case studies. However in the past decade or so only aggregated data have been released to avoid cases being identifiable and being the focus of adverse publicity, and so the patterns associated with particular parental characteristics, the age of child and the cause of death cannot be gleaned. From information I was able to obtain from the Child Death Inquiry Unit about cases involving a parent with an intellectual disability, the Child Death Review Panels included the following recommendations:

- The need for a more comprehensive family assessment
- The need for a greater understanding of the parental level of functioning and how this impacts on parenting capacity
- Engagement with appropriate family support services for parents with an intellectual disability – their availability, accessibility and their linkages with other relevant service providers
- Consideration of priority access to family support services for parents with an intellectual disability
- Provision of training for both child protection and intellectual disability staff based on examples of effective interventions with parents with an intellectual disability
- Skill development for intellectual disability workers with regard to parenting and family issues

- Importance of service collaboration and mutual consultation between child protection and intellectual disability

Most children protection deaths involve children under the age of two years. These can entail neglect, such as the failure to seek medical intervention for a baby with pneumonia who is already undernourished, or be the result of physical abuse such as shaking an infant. In my conversation with the chairperson of one of the Child Death Panels involving a somewhat older child who died from injuries inflicted upon her, the heightened vulnerability associated with intellectually disabled mothers repartnering were identified, especially where the child was seen as an obstacle to the success of the relationship. This of course is also true of mothers who are not intellectually disabled. In this child's case, the warnings from the family support worker about the excessive use of time-out, to the degree that the child was virtually imprisoned in her bedroom were disregarded.

There is strong data to indicate that male partners entering a household who are not the child's biological father also pose a greater risk than biological fathers of physical and child sexual abuse. In relation to sexual abuse by mothers there is very little data, and it may be purely coincidental but the only two cases of maternal sexual abuse in which I have been involved both involved intellectually disabled single mothers who slept with their sons and fondled their genitals. Case studies, of course, are useful for hypothesis generation but do not provide a basis for generalization.

The CASIS data on children whose parents have an intellectual disability is very useful but needs to be seen within the broader context of the child protection system. Each year in Victoria there are approximately 40,000 notifications of alleged child abuse and neglect made by professionals, relatives and members of the general public who are concerned about particular children. (The number of children is far lower than 40,000 as over 60% of the referrals have been the subject of at least one previous notification).

40,000 notifications

13,000 face to face investigations

7000 "substantiated" cases of abuse or neglect

3000 Protection Applications.

At any one point in time there are approximately 4000 children on statutory orders, the majority of whom live at home with their parents. Court orders are typically for 12 months and 60% of children currently on a court order have been on previous orders. Thus the current child protection system in Victoria continually recycles cases at both the pre-Court and post-Court levels. It is extremely unstable for children – 65% of children in out of home care on June 30, 2001 had had four or more previous placements.

Approximately 80% of families investigated for alleged child abuse are poor, with a massive 63% of cases investigated having a parent(s) dependent on a benefit or pension. A breakdown of parental characteristics in substantiated cases in 2000-01 found that in 228 cases or 3%, the parent(s) had an intellectual disability. This is a much smaller group than parents with a psychiatric disability or substance dependence. For comparison:

- 3% had an intellectual disability
- 4% had a physical disability
- 19% had a psychiatric disability
- 31% had an alcohol dependence
- 33% had a substance dependence
- 52% involved domestic violence

Data on the level of overlap between intellectual disability and other characteristics in the substantiated cases is not available but in a very recently released DHS report (Public Parenting, A Review of Home Based Care) this is provided for children placed for the first time in foster care in the years 1997-98 through to 2001-02. This is very likely to be a more problematic group of cases than those who remain at home with their parents with an intellectual disability. (The Report actually only gives percentages but I was able to obtain the following data from DHS).

From 1997/98 through to 2001/02 there were 171 children or an average of 34.2 per year who entered foster care for the first time and where parental intellectual disability was identified as a “primary characteristic”. In the year 2001/02 the number fell to 24 (this may reflect a recent trend to placing children with relatives rather than with unrelated foster families but the data on this type of care is not available). In a very significant

proportion of these 171 cases there were at least two parental characteristics. (Due to the multiplicity of characteristics in some cases the figures total more than 171 cases):

- 34 (20%) also had a physical disability
- 54 (32%) also had alcohol related problems
- 54 (32%) also had a psychiatric disability
- 93 (54%) also involved domestic violence
- 43 (25%) also had a substance dependence

I expect many will find this surprising, but perhaps again coincidentally, the family with whom I worked on my sabbatical leave in an intensive home-based service to assist with the reunification process, reflects this profile. The mother had a psychiatric disability and an intellectual disability, a tendency to violent outbursts, and on some occasions would misuse alcohol. Her 5-year-old son also fitted the statistical profile of children in the child protection system, having had four placements in the 8 months prior to his reunification with his mother, two with relatives and two with foster families. Not surprisingly he developed an attachment disorder and severe behavioural problems and was subsequently excluded from his primary school because of his extreme violence to other children. His mother also behaved in a very threatening manner to other children in the playground. It is very easy to dismiss such examples of exclusion as prejudice but I believe that such a construction fails to consider the rights of other children to a safe environment. This little boy was subsequently taken into care when his mother physically abused him, and experienced further temporary placements before being eventually placed in permanent care with a family, with continuing contact with his natural family. Sadly, like many boys with conduct disorders who are placed over the age of seven, this arrangement finally broke down due to his persistent conduct disorder. I do not know what has happened to him since but if his fits the statistical profile, the chances of a positive outcome are poor.

It is worth noting that this case had the very best that our system had to offer in terms of intensive, in home, family based intervention (up to 20 hours per week) underpinned by strong behavioural management. The family also had the very best early intervention that was available in this State - a four month intensive family residential program specializing in serving parents with an intellectual disability and their children, and follow-up family

support and a specialized day care program. It is also worth noting that these two services were defunded under the Kennett government. This case provides an illustration of what may sit behind the statistical picture of that small sub-group of families whose children end up in out of home care. The DHS data outlined above on the complexity of these cases suggest that:

1. A relatively small number of children of parents with an intellectual disability where child abuse or neglect has been substantiated are actually placed outside their families each year (in the range of 10% to 20% of substantiated cases in which a parent has an intellectual disability).
2. The high level of associated problems in these cases constitute an atypical group of parents with an intellectual disability, and poses a serious risk to children.
3. The complexity of dual diagnosis cases means that "single input services based on categorical funding" (eg intellectual disability, mental health, domestic violence, alcohol/substance dependence) are likely to have difficulty in meeting the needs of this client population.

I have been asked to address 4 questions:

1. **The problems with the current child protection system for parents with a disability** (I would add "and their children!").
2. **How good the current child and family welfare system is at supporting parents with an intellectual disability and their children**
3. **The tension between child and parent rights and the challenge, if any, this poses for family centred practice.**
4. **How could the system of child and family support change to better meet the needs of those families and what do you consider the barriers to this change?**

The problems with the current child protection system for parents with a disability *and their children.*

The **major** problems with the current child protection system for parents with an intellectual disability and their children are the same for all parents and their children involved in the child protection system.

- It is a grossly overloaded, investigation-driven system which largely recycles the same children in which the primary question becomes not “how is the child and how might we assist the family?” but “do we have a threshold of evidence which requires statutory intervention (and if not, close the case)?”. Thus many families do not receive the assistance, which **might** prevent child abuse or neglect.
- For children who need out of home care, the current system does not provide stability. This is a recipe for attachment disorders and conduct disorders, and these conditions make it very hard to natural parents to cope if the children are returned home, and if they remain in foster care, they are likely to precipitate further placement breakdown, thus creating a vicious cycle.

In the foreseeable future, the child protection system will remain investigatory in focus as this is all it can do in the face of a high level of notifications, and screening for statutory intervention and supervising cases under statutory orders are its core responsibilities. I should add there have been admirable initiatives by the Department aimed at prevention and diversion but these are constrained by the limits of funding available from Treasury. (The situation in NSW is very different – an additional \$1.2 billion having recently been allocated to child protection over the next 4 years).

Thus the main problems for parents with an intellectual disability, like other parents, are insufficient support services to prevent situations arising where people in the community (professionals, relatives and the public) feel morally and/or legally obliged to make a notification to the child protection service, and where this cannot be prevented, there are insufficient resources to assist in the prevention of its recurrence.

How good the current child and family welfare system is at supporting parents with an intellectual disability and their children?

This question seems to ignore the fact that the child and family welfare system is only one part of the wider range of health, education and social welfare services responsible for supporting parents an intellectually disability.

- obstetric hospitals - ante-natal assessment, follow-up and referral
- maternal after care and family admission facilities (eg Queen Elizabeth Centre) which can provide intensive early intervention and skilled assessment of the adequacy of the care an infant is receiving
- local maternal and child health services which can provide some home-based support and referral to other services
- disability services with a family centred perspective, which can work with the parents in relation to parenting roles and strengthen extended family and social network supports for disabled parents and their children.
- family support services in child welfare NGOs with sufficient expertise and resources to provide long-term support (eg more than the current 4 month maximum for family support intervention)
- high quality day care centres which can provide a stimulating, stable environment for children below school age, lowering the risk of environmentally-induced developmental delay and potentially working with parents to enhance their capacity to stimulate and nurture their children
- primary schools which can engage with the parent and meet the additional needs of children in relation to literacy, social relationships and the problems which can arise for children in relation to their parents' disabilities (eg parental dependency, lack of advocate re school issues, and stigma among peers)
- secondary schools which can provide the additional supports required to assist adolescents continue with their education and to manage the problems which can arise for them in relation to their parents' disability

However, it needs to be acknowledged that not all cases of child abuse and neglect can be prevented, even with well-resourced primary and secondary prevention services, and so some cases will inevitably enter the child protection system. Once the child is within the

child protection system, there is one main aspect of the system which does pose a particular problem for parents with an intellectual disability, and that is participatory decision-making processes which do not make sufficient allowance for the parent's cognitive limitations. The same is true for the participation of children and young people in the decisions, which concern them.

The tension between child and parent rights and the challenge, if any, this poses for family centred practice:

In cases in which children have not been harmed and are not at risk of being harmed, the interests of intellectually disabled parents and their children are not in tension. When harm or the risk of harm is present, there is a tension, and in principle it is accepted that the child's rights are paramount.

For example in the Preamble to a Resource for Disability Service Providers on establishing parenting groups for parents with an intellectual disability it is stated that:

"The child is the most vulnerable member of the family and the least able to exercise his or her rights. The highest priority for any worker or program is to ensure that the child's physical and emotional needs and safety are never jeopardised by the needs of the parent."

In that hard to find Protocol between Protective Services and Intellectual Disability Services, August 1993, it is similarly stated that:

"The welfare of the child is the paramount consideration regardless of who is the client – ie the rights of the intellectually disabled parent never override the rights of a child or young person to protection."

In practice however, many in the child welfare system believe that the current legal framework fails to uphold this principle. The legislation **and the way in which it is currently enacted in this State** places such emphasis on the least restrictive option that significant harm is inflicted on many children who are subject to court orders. This is

especially true for those children subject to repeated court orders and where placement prevention and family reunification have failed. Unless these children can be raised by their extended family they drift from foster placement to foster placement. In most other child welfare systems in the world these children would be placed in a permanent substitute family.

How could the system of child and family support change to better meet the needs of those families and what do you consider the barriers to this change?

The major requirement of child and family support service is additional resources, which include skill development as well as sufficient personnel to provide what in many cases will need to be long term support.

However, the question is again based on the assumption that the primary focus should be on child welfare services. In my opinion adult mental health services, intellectual disability services and substance dependence rehabilitation services are generally better equipped to respond to the needs of the children of their adult clients than child welfare services because:

- they have already engaged many of the parents in relation to their own needs
- they have more expertise to work effectively with the parents than most generalist child welfare agencies
- they do not induce in parents the same concerns about child protection intervention

For Disability Services to perform this role:

- parents must be willing to receive a service
- service providers must have a strong duty of care to children
- service providers must have sufficient child-related knowledge
- additional resources need to be available

Secondary consultation by child welfare agencies would be useful. This already happens in some places. For example, in one DHS region where disability services and child protection services are co-located, the latter provides consultation around infant needs and child safety, and avoids becoming directly involved with most families as they trust their

disability colleagues to be mindful of the child's interests. By identifying those locations in which collaboration is currently working well, and understanding better the conditions under which this can occur, we may be able to replicate this in other settings.

If those at the coalface can develop trusting and collaborative relationships perhaps there is some hope for the rest of us to work together to improve the prospects for parents with an intellectual disability - and their children.

Confronting the challenge: The need for a different approach to families where the parent has an intellectual disability.

Dr David Sykes, Manager, Policy and Education at the Office of the Public Advocate.

Marissa

Marissa is a thirty five year old single mother who lives with her five-year-old daughter Joy. Marissa has only one child because she does not feel that she could cope with more than one. Marissa is very family focused with a strong sense of responsibility. She sees her parenting role as being extremely important and seeks to provide Joy with opportunities she missed out on as a child. Marissa sought out a parenting program to further assist the development of her parenting skills but could not find one that could offer the support she was seeking. She is a good mother who struggles to implement strategies around discipline and safety. Marissa has coped with significant personal hardships in her life including being abused physically and psychologically by her previous partner. He was an alcoholic and had threatened to kill both Melissa and Joy. She eventually fled to a women's refuge, taking Joy with her and never returned. Marissa is quite socially isolated. Joy has quite significant behavioural problems and has been assessed as having ADHD.

There have been several notifications in relation to Joy over the years. In the most recent notification, child protection had concerns about the risk another family member posed to Joy and subsequently removed Joy to a foster care placement. In the report by Child protection the main protective concerns were Melissa's intellectual disability and limited capacity to meet Joy's needs and manage her behaviour. During this time access visits were often not supported as promised and the prospect of risk assessments during these visits was implied

The Office of the Public Advocate assisted in organising a court order against the family member in question and disability services worked with Melissa on improving her parenting skills. Joy was eventually returned to Marissa's care and she continues to

receive support from services. This reunification was seen as essential to Joy's ongoing sense of identity and belonging. Melissa still has not had it explained why Joy was removed from her initially and fears her future removal

This case of Melissa and Joy highlight the common themes, which confront parents, usually mothers, with an intellectual disability. These themes are broadly:

- Myths and misconceptions about parents with a disability;
- Lack of suitable support programs available to parents with a disability from both disability services and mainstream parent support agencies;
- Limited knowledge by practitioners of how to work effectively with these families;
- Problems with a system primarily focused upon the detection of child abuse rather than supporting the family;
- Adversarial framework promoting a polarisation of views into two camps of child's rights and parents' rights which undermines a family support approach.

Collectively these issues have been a significant barrier to a more enlightened response to supporting parents. As an advocacy agency concerned with promoting and protecting the rights of people with disabilities in Victoria, the Office of the Public Advocate (OPA) has long held concerns about the barriers which may not only add to the challenges confronting people with disabilities as parents, but which may also condemn the child to an insecure and uncertain future, with potentially destructive consequences upon their development.

My comments today draw upon the experience of the Office of the Public Advocate acting as guardian or advocate for parents with an intellectual disability. I will highlight some of the key elements of this issue with a particular focus on the area of child protection. This focus should not be interpreted to mean that all or indeed most parents with an intellectual disability are likely to be involved with child protection. There are many parents with an intellectual disability who may never become involved in this system and function well as parents. In the recent report by Mathews and Mildon et al (2003) they suggest caution when considering the literature in this area, as the families researched may not be representative of all parents with an intellectual disability. Parents with an

intellectual disability whose parenting skills are adequate may never come to the attention of the service system (Feldman, 1997 in Mildon et al, 2003). Much of this literature also tends to focus on mothers with very little known about fathers (Booth and Booth, 1993 in Mildon et al, 2003). Finally most of the research in this area has tended to focus upon the difficulties and deficits of parents rather than the competencies and positive aspects of the situation (Mildon et al, 2003:3). It is widely known that parents with a disability are disproportionately represented in the child protection system. Indeed the current emphasis upon child protection rather than family support makes this not altogether unexpected.

Intellectual disability

A number of reports in this have highlighted the lack of clarity around what is meant by intellectual disability when considering the research in this area (Office of the Public Advocate and Wesley Central Mission, 1997, Mildon et al, 2003). In Victoria to be registered to receive services under the *Intellectually Disabled Persons' Services Act 1986* the person must be assessed as:

1. having significant sub-average intelligence (i.e.I.Q. <70).
2. having significant deficits in adaptive behaviours.
3. occurring before the age of 18 years.

However, some people may not fit this assessment as eligible clients but still present with cognitive difficulties, which present challenges for their functioning on a daily basis. Therefore when I talk about intellectual disability I am referring to a broader group than that referred to in the *Intellectually Disabled Persons' Services Act 1986*. Having said this, the discussion of intellectual disability is difficult given the actual individual experiences of the person with the disability and the significant range of abilities this includes. Furthermore the actual experience of intellectual disability is quite individual. Therefore we need to be careful not to make any presumptions or assumptions based solely on whether the person has an intellectual disability. This label can also tend to reinforce a focus upon disability rather than ability.

Prevalence of parents with a disability in Victoria

Whilst there are no detailed figures on the number of parents with an intellectual disability, Mildon et al (2003) suggest based on figures from the Australian Bureau of Statistics (ABS), that approximately 1-2 % of Australian families with children between the ages of 0-17 years include at least 1 parent with learning difficulties (ABS, 2000 in Mildon et al, 2003:3). This estimate may hold part of the answer as to why we continue to struggle as a community to respond to the support needs of these parents as issues of mental illness and drug and alcohol abuse probably present a larger challenge to services supporting parents. There is the suggestion in the international literature that the number of people with intellectual disabilities becoming parents is increasing (Ray, Rubenstein and Russo, 1994; Whiteman and Accardo, 1993). This apparent increase may be the result of closer scrutiny of parents and their children, which could bring them into contact with the service system (Booth, 2000).

Myths, misconceptions and prejudices

The discussion of parents with a disability brings with it a significant range of judgements, beliefs and prejudices in relation to disability and parenting. The advocacy experience of the Office of the Public Advocate in these situations is that judgements and prejudices about parents with an intellectual disability are significant in promoting responses, which are sometimes at best unfair and at worst discriminatory, towards families where the parent has an intellectual disability. The most recent report into the issue in Victoria by the Disability Discrimination Legal Service (2002) highlights this in the title "**Pride and Prejudice**".

Indeed in 1997 the Office of the Public Advocate in collaboration with Wesley Central Mission the produced the report titled "**No easy answers**". This report highlighted a series of prevailing myths relating to disability and parenting. These have presented a significant barrier to a more enlightened and flexible response to the needs of these families by the system. The following quote encapsulates the essence of this problem.

“ The idea that people who have a disability are capable and competent people to raise children, challenges established assumptions that people with disabilities should not become parents”.

(Yooralla’s Parents with a disability community project (YPWDPC, 1999: 7).

People with disabilities have historically been discriminated against in all areas of their lives. This was highlighted in the practice of institutionalisation where people with disabilities were forced to live in settings segregated from the rest of the community. They were given little assistance in developing appropriate social skills and living skills. Indeed they were often discouraged from forming intimate social relationships, as there was concern that this may lead to sexual activity. The notion that people with disabilities may wish to be sexually active, and to have children, was abhorrent to many in the community (Ely and Wilson, 1996:22).

Historically women with disabilities have been regarded as incapable of being adequate parents. This has in part been reflected in the practice of routinised sterilisation of women with a disability. This also stemmed out of a belief that they were likely to have children who also had a disability and so this was seen as a way of reducing the number of people with disabilities (Booth and Booth, 1993). An example of this is the argument by eugenicists that criminality, deviance and feeble-mindedness were hereditary and that good stock could and should be bred while bad stock should be weeded out. These views also informed the view that women with disabilities should be sterilised (Office of the Public Advocate and Wesley Central Mission, 1997:6). This myth carries an inherent presumption that disability is something to be avoided.

This also presumes that a woman with an intellectual disability is more likely to give birth to a child with a disability than a non-disabled mother. The reality of this is that a woman with an intellectual disability is no more or less likely to have a child with a disability than anyone else (Office of the Public Advocate and Wesley Central Mission, 1997:10).

Given the continued dominance of many of these myths in the minds of professionals and indeed the wider community, I will highlight three key myths and how they have affected the service response to these families in the context of child protection:

1. That parents with a disability are unable to be adequate parents;
2. Parents with an intellectual disability are unable to learn to become adequate parents;
3. Parents with an intellectual disability are more likely to abuse their children.

In highlighting these myths my intention is not to perpetuate these myths but rather bring them into our consciousness so that they can be dealt with openly.

Myth 1: People with an intellectual disability will be unable to provide adequate parenting

The issue of parenting and what it means to be a good or even acceptable parent is a contentious area where a wide diversity of views, values and beliefs are evident.

Whittaker highlighted the fact that:

“Parenting is not completely instinctive; parenting is a tough and demanding job; parents most of the time desire and try to do the best for their children; parents want and need support information and reinforcement in their parenting role; parents are also people with their own needs as adults”.

(Whittaker, 1985).

The absence of any minimum standards of parenting mean that this is very much determined by values and beliefs (Tymchuk, 1992).

In summary:

“...[T]o speak collectively of ‘parents who have a disability’ is as foolish as trying to speak collectively of ‘parents’ generally-as though they belong to some homogeneous group who share identical experiences of impairment, disability and parenting” (Fuller, 1996:5)

The Australian research conducted into the parenting capacity of parents with a disability has generally discounted any suggestion that intellectual disability per se is a good predictor of parenting competence and there is evidence that when parenting deficiencies do exist these are to a large extent remediable (Feigan, 1993; Booth and Booth, 1993; Budd and Greenspan, 1985; Dowdney and Skuse, 1993; Feldman, 1994; Llewellyn, 1990; Tymchuk and Feldman, 1991).

However, the advocacy experience of the Office of the Public Advocate and Mildon et al (2003) in child protection matters is that psychologists use adult IQ tests routinely when assessing a parent with an intellectual disability. This reliance upon IQ tests continues despite research demonstrating that parental IQ is a poor indicator of parenting ability (Schilling et al, 1982). These assessments are frequently used to imply a range of parenting deficits, including limited capacity to learn appropriate parenting behaviours (Mildon et al, 2003:7). Indeed, in the context of child protection, research has shown that there is a tendency to base a finding of incompetence to care on the basis of disability alone, without conducting a more comprehensive assessment and providing appropriate support services (Llewellyn, 1990:374).

This approach also supported more of a focus upon deficits. Certain deficiencies may also be falsely attributed to the disability when they may in fact stem more from social constraints such as poverty, social isolation, poor housing and the inadequacy of support services (McConnell, 2000:85).

“Cognitive assessments alone are not sufficient to address how parenting difficulties may be overcome and how individual families and their families may be best supported”
(Mildon et al, 2003:7).

arah

Sarah has had her capacity to parent assessed on at least two occasions and in both instances was considered capable of parenting. These assessments occurred in the context of concerns raised about Sarah's capacity to parent in a child protection investigation. However, despite these assessments, child protection sought further assessments to prove the contrary.

Sarah's case highlights the prejudicial attitude, which is sometimes held towards parents with a disability.

When an assessment is made of the capacity to parent of a person with an intellectual disability, there is significant potential for this assessment to be influenced by the assumptions held by individual workers (Mildon et al, 2003; McConnell et al, 2000). In the child protection system context, the use of risk assessments is particularly problematic because they are often perceived as semi-objective means of determining the potential for parents to provide for the health, safety and well being of their children (Mildon et al, 2003). Yet McConnell (2000) argues that the concept of risk is not a value neutral concept and that this is heavily influenced by one's perceptions of the ability or otherwise of the parents. Consequently a negative view of parent's abilities is likely to result in perceiving an increased risk, whilst a positive view of parent's abilities is more likely to result in perceiving a lesser degree of risk. There has been little attention given to the way workers views inform their perceptions of risk (McConnell, 2000).

Moreover such risk assessments have been found to be an unreliable means of predicting future neglect and abuse of children (Goddard, Sanders, Stanley and Tucci, 1999). Consequently whilst risk assessment is promoted as a quasi-objective means of determining the potential of the parental situation to provide for the health, safety and well being of the child, this fails to acknowledge the absence of a sound theoretical and empirical basis to the concept of and measurement of risk (McConnell, 2000:84).

Indeed selecting sound assessment methods as well as a capacity to successfully engage with parents are highlighted by Mildon et al (2003) as being critical in the effective

assessment of families. They identified a number of attitudes that are considered to be helpful to the assessment process. These include:

- A hopeful and positive view of parents and families;
- A belief that parents are experts on their own lives and this expertise is acknowledged and valued;
- A belief that most parents are capable of positive behaviours;
- A belief that most parents are active problem solvers;
- Change is achieved through a learning process.

(Mildon et al, 2003:12).

Parents with an intellectual disability face the same challenges as many other parents. Many parents with an intellectual disability are adequate or better than adequate parents, and with appropriate support there could be many more (Hayman, 1990). The challenge for the community and professionals is to be able to approach each parent as an individual without over-generalising from a label, which may provide limited information about an individual's capabilities or deficits (Budd and Greenspan, 1981).

There are a number of factors, which can cause parents to provide inadequate care: marital harmony; experiences from family of origin; and socio-economic factors (Mira and Roddy, 1980; Greenspan and Budd, 1986).

Socio-economic factors

Parenting occurs in a socio-economic context. However, socio-economic differences have been largely ignored in research of intellectually disabled parents (Llewellyn, 1990:273). People with a disability are disproportionately represented amongst the socially disadvantaged in Australia. In a study by the Social Policy and Research Centre (2000) it was found that:

- 26.7 % of people with a disability in Australia live below the poverty line;
- People with a disability are more likely to have lower levels of educational achievement than other groups;
- People with a disability more likely to be unemployed. In 1998, 11.5% of people with disabilities were unemployed, compared to 7.8% of people without a disability;

- People with a disability are more likely to have health problems that significantly affect their quality of life.

(Social Policy Research Centre, 2000)

This social disadvantage can often have greater implications for the person's capacity to parent effectively than any aspects of their disability. In a study by Feldman (1998) poverty was identified as a major factor affecting parenting capacity.

In a recent United Kingdom report it was highlighted that:

"Given the increasing recognition of the link between poverty and households that contain disabled members and more particularly disabled adults, the economic situation of families must be recognised as a key factor in an analysis of the situation of disabled parents" (Wates, 2003:57).

This factor also emerged in a study of Victorian families involved with the child protection system in 2000-01 where more than 75% of families investigated were on low incomes, 63% were in receipt of a pension or benefit and 45% were sole parents (Dept. of Human Services, 2002:2).

In addition to poverty, other research has also highlighted the impact of other factors, which have a greater impact upon the capacity to parent than disability (Tymchuk and Feldman 1991; Llewellyn, 1995; Feldman, 1997) (Forehand, Lautenschlager, Faust and Graziano, 1986; Hops et al., 1987; Webster-Stratton, 1998 in Mildon et al, 2003). These factors include:

- Substandard housing;
- Insufficient social supports;
- Social isolation;
- High stress levels;
- Own experience of being parented;
- A history of maltreatment;
- Depression and poor self-esteem;
- Little exposure to day-to-day family life in their childhood;

- Homelessness;
- Inability to access the formal service system;
- Access to competency –enhancing supports (both formal and informal);
- The temperament, personality and specific needs of each child.

Many of these factors are related to negative child and parenting outcomes (Booth and Booth, 1993;Feldman, 1997; Kelley, Sikka and Venkatesan, 1997; in Mildon et al, 2003)(Feldman and Walton-Allen, 1997) (Keltner, Finn and Shearer, 1995) (Scott, 2000) (Booth and Booth, 1994, McConnell et al, 2000).

Interestingly in the report by Swain et al (2002) child protection workers believed that parental disability was rarely the sole factor in interventions. In fact most parents with disabilities coming to the attention of child protection system also displayed other risk factors such as:

- Poverty;
- Homelessness;
- Alcohol and/or drug use; and
- Deprived backgrounds.

Indeed the parent's own childhood background and experience of being parented was seen as important, together with their own age at the time of the child's birth. In this same report where an audit was conducted of Children's Court files it was found that parents with a disability were disproportionately represented as having other factors present which adversely impacted upon their capacity to parent. These included:

- Frequent family moves or homelessness;
- Current or previous experience of domestic violence;
- Substance use during pregnancy;
- Limited access to antenatal care;
- Previous experience of abuse or parental admission to care as a child

(Swain et al, 2002:33).

There was also a survey of the family characteristics of 387 children in care in Victoria in 2001. In summary these findings found that these families:

- Were larger than average;
- Had a higher reliance on income benefits and pensions and therefore higher rates of unemployment;
- Had higher rates of substance abuse;
- Had a higher number of single parents;
- Over 40% of fathers and 14.5% of mothers play no part in the lives of their children, due to the fact that they are either deceased or their whereabouts are unknown (Dept. of Human Services, 2001a: 20).

Many parents struggle to care for their children amid the daily pressures imposed by poverty, poor social, family and community support, single parenthood, poor access to information, multiple service providers, entrenched stigma and increased surveillance (Fuller, 1996:10). These factors can often be linked to backgrounds of social and emotional deprivation (Office of the Public Advocate and Wesley Central Mission, 1997:7). This can lead to difficulties in the person having poor social skills and increased vulnerability due to limited personal or social defences and indeed many may have experienced abuse as a child (Nyberg, 1996).

In the context of child protection matters, Glaun and Brown (1999) undertook a study of twelve cases involving mothers with an intellectual disability involved in the Victorian Children's Court Clinic and found that the weight of other stressful factors including emotional, physical, health and environment considerations appears to have precipitated a breakdown in coping with consequential neglect of the child (1999:103).

High risk infant teams are specialist teams within the child protection system, who provide case management and monitoring in children less than two years of age who are notified to child protection. Data from High-risk infant teams in 2000 suggests that 14% of the mothers they had contact with had an intellectual disability. However, interestingly, other risk factors identified were significant sole maternal representation (40%), poverty and material crises (34%); significant presence of domestic violence, evidence of chaotic

family situation, indication of substance abuse and social isolation (Dept. of Human Services, 2001:24).

The ordinary challenges of parenting can be exacerbated by the additional stressors parents face in their socio- economic circumstances (Feldman, 1997). This is in addition to any parenting difficulties they may face as a result of their disability and the intense scrutiny they are generally under from the service system (Swain et al, 2002; Mildon et al, 2003). Unfortunately the consequence of these factors for the individual's capacity to parent is too easily overlooked in any assessment of parenting.

Myth 2: Parents with an intellectual disability are unable to learn, apply and maintain adequate parenting knowledge and skills

There can be a perception that people with an intellectual disability are not capable of learning and consequently are only capable of monotonous and repetitive tasks. These conceptions of disability can lead to:

1. Parents being considered incapable of parenting solely on the basis of having a disability and without any evidence of incompetence;
2. Child maltreatment being anticipated without any specific evidence;
3. The parent being thought incapable of learning and thereby overcoming parental deficiencies if these exist;
4. Parenting difficulties being blamed on the parents' disability rather than any other difficulties in the parent's life, such as poverty, social isolation, poor housing and the inadequacy of support services (McConnell, 2000:83).

Whilst this theory has largely been discredited, there is still widespread concern about the extent to which people with intellectual disabilities are capable of being parents (McConnell et al (in press) in Mildon et al, 2003).

Parents with an intellectual disability are as capable as other parents of learning, applying and maintaining parenting skills. However, the interventions and service response need to be matched to parental learning characteristics (Feldman, Case and Sparks, 1992). A number of researchers have identified that current practice does not reflect best practice in terms of teaching parents the skills they need for effective parenting (Mildon et al,

2003: 6). Feldman et al (1998) found that verbal instruction and brief demonstration were sometimes used. However if it were found that the parent failed to understand, then rather than trying a different method of teaching, the child would often be removed on the grounds of a judgement that the parent was not able to learn (Mildon et al, 2003; Hayman, 1990). When the teaching methods are matched to their learning needs, parents with an intellectual disability can learn, retain and generalise parenting skills taught to them through discussion, modelling, feedback and reinforcement (Mildon et al, 2003:6).

Often people with disabilities are socially isolated as a result of limited opportunities to form and experience respectful peer relationships. This can also be the result of loss of trust and confidence in others. This can be further reinforced where a trusted worker moves on continuing this history of rejection (Office of the Public Advocate and Wesley Central Mission, 1997:7). In a recent study by Feldman et al (2002) mothers with an intellectual disability were asked to list the variety of supports they receive. The most frequent support provided was that offered by workers followed by family and friends. This is of concern given the high turnover of workers can make this support infrequent and inconsistent. This can also be confusing for mothers as different workers may give them conflicting advice. One mother I advocated for became angry at being told by a family support worker to do things differently to the way a previous worker had suggested.

Myth 3: Parents with an intellectual disability are more likely to abuse their children

Child abuse occurs for a number of complex psychological, social and personal reasons. Parents with a disability have sometimes been regarded as likely perpetrators of child abuse and neglect (Hayman, 1990; Tomison, 1996a,b, Westbrook and Chinnery, 1995; McConnell, Llewellyn and Bye, 1997). This has not been borne out in the international research, which has clearly demonstrated that 'disability' is not a causal factor in child maltreatment or parental inadequacy (Dowdney and Skuse, 1993;Llewellyn, 1990; Tymchuk and Feldman, 1991; Westbrook and Chinnery, 1995). Neglect of children, where this does occur, can be associated with a lack of training and support (Tymchuk, 1990).

The absence of suitable societal or familial supports that would normally help to prevent neglectful conditions is more useful as a predictor of neglect, irrespective than whether or not a parent has an intellectual disability (Tymchuk, 1990).

Over representation of parents with an intellectual disability in the child protection system

In Victoria, parents with an intellectual disability are over represented in matters before the Children's Court. Between 1996-97 and 2000-01 the percentage of parents with an intellectual disability involved in substantiated cases of child abuse has increased from 2% to 3% (with a peak of 4% in 1997-98) (Dept. of Human Services, 2002:27). This is quite significant if we consider that the percentage of the Victorian population with an intellectual disability is less than 1%. In this same study 30% of cases that proceed to the Children's Court are where one or both parents have an intellectual, physical or sensory disability (Dept. of Human Services, 2002:53).

In the study by Swain et al (2002) an audit of 87 Victorian Children's Court cases was conducted. Of these, 30% involved parents with disabilities suggesting that parents with disabilities appear more likely to have concerns raised about their parenting ability than do parents without a disability. Swain et al (2002) also concluded that parents with a disability appeared to:

- Be fearful that contact with welfare and disability services workers would result in a notification to child protection services. Consequently they may not access necessary services.
- Be more likely to receive disproportionate scrutiny of their parenting capacity.
- Have little or no understanding of or control over the direction of child protection interventions into their parenting capacity.
- Be at a disadvantage in Children's Court proceedings in the absence of specialist support and adjustments.
- Have inadequate access to affordable childcare, access to foster or respite care and other supports and services. (Swain et al, 2002:ii)

Indeed the advocacy experience of Office of the Public Advocate in child protection matters also reflects these issues.

A similar study of the prevalence of parents with a disability involved in protection cases in the Children's Court of NSW by McConnell et al, (2000) found that a quarter of all cases involved parents with a disability. Moreover approximately one third of the total Department of Community Services Care applications to the Children's Court involved parents with a disability (McConnell, 2000). This represented a significant over representation of parents with a disability in these proceedings. This study identified several key factors, which influenced these outcomes:

- Attitudes towards parents with a disability;
- The concept of risk;
- The opinion of experts;
- The lack of suitable support services;
- System constraints;
- The court environment. (McConnell, 2000:82).

Cases where there is an investigation but no substantiation of abuse can have a particularly detrimental impact upon the families concerned. In 2000-01 31.6% of cases involving parents with a disability were the subject of more than one notification (Dept. of Human Services, 2001b: 22). This highlights the level of scrutiny and trauma often experienced by these families as a result of repeated notifications.

Incidence of child removal from parents with an intellectual disability

Given the over representation of parents with an intellectual disability in the child protection system what do we know about rates of child removal in these cases? In a study of 77 South Australian parents with intellectual disability, one third of their children had been taken into care (Bowden, 1994). In the study for the NSW Children's Court there were significant differences in the outcomes for parents with a disability, with children more likely to be subject to wardship orders and a disproportionate number of children being placed out-of-home (McConnell, 2000:82). A New Zealand study found

41% of children had been removed in a study of 46 parents with an intellectual disability (Mirfin-Veitch et al, 1999).

Similar trends are evident in the overseas literature. In the United States, Accardo and Whiteman (1989) found 45.5% (103 of 226) of children born to 79 families headed by a parent with an intellectual disability had been removed. In St Louis 45.5% of children (103 of 226) "born to parents with learning disabilities had been removed from the family home" (Accardo and Whitman, 1990:8). In Sweden a figure of 45% removal of children was found in a study of 40 children with mothers who have an intellectual disability (Gillberg and GeijerKarlsson, 1983). Recent studies in Germany (Pixa-Keltner, 1998) and Denmark (Faureholm, 1996) found that 30% of children born to parents with disabilities were involved in child protection systems and placed permanently out of home.

What is not considered in the systems' response to parents with an intellectual disability is the potentially harmful impact of removal upon the child and the failings in the current foster care system. The experience of out of home care for many young people is less than ideal with many children experiencing multiple placements (Dept. of Human Services, 2002:3). The Auditor General's report of 1996 into out of home placements noted.

"system abuse caused through the separation of sibling groups and multiple placements due to more appropriate placements not being available"
(Dept. of Human Services, 2002:52).

Therefore we can conclude that not only are parents with an intellectual disability disproportionately represented in child protection matters, but also they are also more likely to have their child removed and placed in care. Whilst these findings are of significant concern, the overrepresentation of parents with a disability in care and protection proceedings has been used to support assertions that parenting failure is inevitable. (Shilling, Schinke, Blythe and Barth, 1982).

"Instead of just looking at the situation and seeing a parent with a disability and deciding they're not coping, they should be providing better support and providing information on

alternative ways to parent effectively. Don't be so quick to judge. It doesn't mean that some kids don't need to be removed but it's important to find out why parents with disabilities are coping the way they are". (Swain et al, 2002:52)

The rights perspective

The question of rights is often raised in this area, particularly in relation to child protection matters. The rights of the parent, child and family are enshrined in various UN declarations. In relation to the rights of parents with a disability there are a number of UN declarations, conventions and covenants which all emphasizes the importance of the family and that it is important for a person to live with his or her own family and also that families need support in caring for children. This is specifically recognised in the Declaration of the Rights of the Child (Office of the Public Advocate and Wesley Central Mission, 1997:15). It is also acknowledged that it is a basic human right to have children, and that this right may conflict with the rights and interests of any resulting children (Office of the Public Advocate and Wesley Central Mission, 1997:15).

In the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities specific reference is made to disability and parenting:

“ States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood”

(UN standard rules, 1993)

The UN convention on the rights of the child, which Australia ratified in 1990, details some key rights of the child. These include:

- Putting the best interests of the child first. These interests fall into essentially three categories: General physical, emotional and intellectual care, Developmental and autonomy;
- Respecting the responsibilities, rights and duties of parents to give the child guidance and direction;

- Ensuring that children survive and develop to the maximum extent possible;
- Protecting children from neglect, abuse and sexual exploitation;
- When children are placed in care ensuring that their right to periodic review of their treatment and placement. (Office of the Public Advocate and Wesley Central Mission, 1997:15).

Unfortunately the application of a rights framework to this area sometimes becomes problematic when it is placed within the adversarial approach adopted in the Court context. The use of an adversarial process tends to promote a position whereby child protection is required to advocate for the rights of the child and consequently any position adopted counter to this may be interpreted as advocating the rights of the parent. Some child protection workers also sometimes see the rights of the child as being mutually exclusive of parents' rights. Indeed some disability advocates could be accused of taking the reverse approach in relation to parent rights.

A single focus on rights from a parent or child perspective often creates difficulties in attempting to preserve the importance of relationships to all family members. This polarisation of the debate has served to make it even harder to deconstruct the myths and misconceptions, which pervade the service and legal responses to parents with a disability. This also makes it difficult to take a more family centred approach when it is perceived that the best interests of the parent and child are somehow mutually exclusive.

The balancing of child and parent interests is one of the greatest sources of stress for child protection workers. However, it is important that this balancing act cannot be achieved by ignoring or minimising the rights of parents with a disability. Nor can it be achieved by applying the law in discriminatory or prejudicial ways (Swain et al, 2002:24).

Current system response

Currently the availability of suitable parent support programs across the State for parents with a disability is at best patchy and at worst non-existent, whether this is a generic parent support program or more specialist disability focused programs. The system is plagued by:

- A lack of co-ordination and collaboration;
- Lengthy assessment processes;
- Significant delays in accessing services;
- Strict eligibility criteria such as age of the children or indeed needing to be referred by child protection;
- Limited knowledge of disability amongst generic programs;
- Limited duration of the programs;
- Different approaches to parenting support by agencies and staff create confusion for parents;

McConnell et al (2000) highlight the extreme difficulty in identifying suitable supports and services for parents with a disability. They also suggested that the attitudes and beliefs of many professionals and agencies led to expectations that parents with a disability could only manage 'adequately' if provided with intensive, even 24 hour support. This is despite clear evidence both locally and internationally that parents with a disability as a group do not require such support. Some parents can manage independently, some will need minimal support and some will need more intensive supports possibly on a daily basis but not normally for the entire day (McConnell et al, 2000:85).

We currently have a system in Victoria where the primary focus is around mechanisms seeking to protect children through the identification of situations of potential child abuse. Whilst this is an important function of any child welfare system this focus in terms of direction and resources has often been at the cost of providing adequate programs to support parents in order to minimise the chances of children being placed at risk.

In Victoria the expenditure on child protection and placement services has increased by 40% since 1996-1997 (Dept. of Human Services, 2002:2). This focuses on notifications, investigations and court applications as well as placement and support. It is recognised that greater emphasis should be given to preventative measures, such as family support services, strengthening families program and Maternal and Child Health Enhanced Home Visiting Service. However only \$26 million was given to such services in 2000-01 compared

with \$178 million for child protection and placement services in Victoria (Dept. of Human Services, 2002:52).

This has had the consequence of not only disadvantaging parents generally but also if you have an intellectual disability this has meant that you are even less likely to be able to access many parenting support programs. Ironically to be able to access some of these parent support programs you need to be referred by the child protection service. This is not a proactive response where parents themselves may seek to improve their parenting skills, like Marissa mentioned earlier.

A recent audit of Australian child welfare programs found a significant trend towards developing preventative strategies (Tomison and Poole, 2000). Three critical aspects to these preventative strategies were:

1. Promoting resilience by focusing on a family's potential for change rather than on their problems;
2. Early intervention services;
3. Whole of community approaches which recognised the broader socio-economic system in which the family are embedded.

These more preventative services also offer potentially significant cost savings in reduced welfare involvement at subsequent stages. Unfortunately the absence of accreditation and practice standards in the parent support area means there is often a significant range in the type and indeed quality of services offered (Dept. of Human Services, 2002:49).

A UK report considering the issues facing parents with all types of disability was titled "It shouldn't be down to luck" (Wates, 2003). This title summed up the experience of many parents with disability as they found it difficult to find out about services and had a fairly inflexible response to the needs of parents, which tended to focus on what the parent was not doing well rather than what they were doing well. They also feared that their children might be removed. They also tended to be reluctant to ask for help for fear that would be assessed as being unable to cope. (Wates, 2003).

Many parents with a disability are wary of approaching various welfare services for assistance because they are often subject to much greater scrutiny of their capacity to care than are other non-disabled parents, despite evidence that a significant percentage of intellectually disabled parents provide a level of care that is acceptable by community standards (McConnell et al 2000). In contrast to this the study by Swain et al (2002) had child protection workers of the view that a number of parents self-reported. This may reflect the desperation of these parents to seek support. It is also interesting to note that with some services they can only be accessed through a referral from the child protection service.

The direction of change outlined in the Integrated Strategy for Child Protection and Placement services in Victoria is to be welcomed as it highlights the importance of the preventative measures and focuses on strengthening families. Indeed the need to respond more flexibly to the often complex and long-term needs of vulnerable families is particularly important (Dept. of Human Services, 2002a: 55).

The key elements of this service system would include:

- An alternative intake phase to link families to support;
- Case management to co-ordinate these services;
- Recognition of longer-term work and assertive outreach.

(Dept. of Human Services, 2002a: 67).

However, unless the Integrated Strategy for Child Protection and Placement services, is adequately resourced and considers how to best respond to the needs of parents with an intellectual disability and indeed other vulnerable families, then these families will continue to be further disadvantaged by a system that is often prejudiced against them.

Conclusion

The response to the needs of families where the parents have an intellectual disability continues to be a poor reflection upon our community. Current efforts to address the issue through individual parenting programs, protocols between Child Protection Services and Disability Services and individual support programs for parents with a disability have contributed to the knowledge and service base for assisting these families. However, the response remains at best patchy and at worst non-existent in terms of the availability of programs to assist these families.

Interestingly in the area of parents with a mental illness there has been a national strategy undertaken as part of the Second National Mental Health Care Plan, 1998-2003. This strategy has involved researching effective community-based interventions, evaluating the effectiveness and sustainability of preventative initiatives, and developing positive outcomes for these families (McAllister and Robinson, 2002:2). In the scoping exercise for this plan they identified three key themes:

1. Interventions are required which support the children through improved understanding of mental illness.
 2. Interventions are required that support the parent including more family focused mental health services.
 3. Policy/service-level changes should be aimed at better identifying and meeting the needs of these children and their families
- (McAllister and Robinson, 2002:2)

Part of the reason previous efforts to address the issues facing families where the parent has an intellectual disability have had limited impact is that there has not been a commitment to addressing the needs of this group at a broad policy level.

It is encouraging that in the Victorian State Disability Plan – Implementation Plan, disability services acknowledged the need to work with the Community Care Division on improving access to supports to assist parents in their parenting role (Dept. of Human Services, 2002:30). There was also a commitment to the training of child protection staff on the support needs of parents with a disability.

If we are to see a change in the response to the needs of these families then the a number of actions need to occur including:

1. The commitment in the State Disability Plan to parents with a disability, needs to be developed so that Disability Services recognise their critical role in the provision of these support services for parents, as well as working collaboratively with more mainstream parent support agencies, across the State.
2. Disability Services role in the support of families also needs to be reflected in the support offered through such services as case management, outreach support and respite. The effectiveness of these support programs need to be evaluated.
3. There needs to be a clear commitment in the policy frameworks underlying parenting support to assist these families. This would then enable a more comprehensive approach to the issue similar to that adopted in the area of parents with a mental illness.
4. Mainstream parent support agencies need to receive appropriate resourcing and support in responding effectively to the needs of this group. Ideally this should occur through a specialist parent support agency, which can evaluate the effectiveness of these strategies and continue to promote best practice in this area. There could also be a role for secondary and tertiary consultation of mainstream parent support agencies by this specialist service.
5. This resourcing and support should also be available to other areas including: health services, maternal and child health, school welfare, general practitioners. This will help to maximise the supportive nature of the entire system.
6. A shift towards a more preventative family support focus, in the policies, legislation and practice underlying our existing child protection system. This change would seek to support families in the first instance and then only as a last resort or where the child is clearly at risk, seek to protect the child where these supportive efforts have failed.
7. In the current system of child protection there needs to be a greater advocacy role adopted by disability services in relation to clients involved in protective matters. This will require education and training of disability case managers in relation to the legislative framework in which child protection operates.

8. There needs to be an independent lay advocacy service available to parents who are not eligible to receive assistance from disability services, in order to make sure parents understand their rights in the process at the initial point of contact.
9. There needs to be a review of whether the adversarial process is the most effective in dealing with child abuse matters, and an examination of the possible application of the approach currently used in adult guardianship and administration matters relating to people with disabilities.

There have been some important initiatives in Victoria in relation to parents with an intellectual disability over the past 15 years. Many of the people in this room have been part of those initiatives. However unless a more comprehensive approach is taken to the issue across the whole of government, which sees a shift in the current frameworks used in the areas of disability, child protection and parent support, then the system will continue to disadvantage and discriminate against these families. Only through a shift towards preventative strategies, which seek to support the needs of all vulnerable families in our community, including parents with an intellectual disability, can we truly say that as a community we are strengthening every family.

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Victorian Parenting Centre Warren Cann & Robyn Mildon

Before I begin, I would like to thank you all for participating in this exciting and important event. There is no doubt about the timeliness of this meeting. At both a social and community level, there has been a renewed focus on parents who have an intellectual disability. Many of you would have seen the 4 Corners program recently aired on ABC television, a good example of the interest and controversy generated by this issue. In the health, welfare and educational fields, the issue of supporting parents with an intellectual disability has never been more pressing. It is apparent that the welfare system is becoming more and more aware of the presence of learning difficulties among the families they serve.

The Victorian Parenting Centre turns six years old next month. For about half of that time, the Centre—in partnership with the Department of Psychology and Disability Studies at RMIT University—has actively pursued opportunities to develop programs and conduct research in this critical area of parenting and family support. As a result, parenting with learning difficulties is now a major plank in an ongoing stream of research being conducted at the Centre looking at effective parenting interventions with vulnerable families. A good example of a recent resource we have produced in this area is the Best Practice paper titled *Understanding and Supporting Parents with Learning Difficulties* which is available on the Centre's website (www.vicparenting.com.au).

At this point I would like to take the opportunity to acknowledge the Apex foundation and more recently the Commonwealth Department of Family and Community Support for their funding support in this period.

Overview of this presentation

Presentations like today create a wonderful opportunity as well as a tricky dilemma: that is, what to focus on in 30 minutes. Given where the Centre's expertise lie, my focus today is on issues related to program delivery and professional practice associated with effectively working with parents who have learning difficulties.

There is a context and a set of assumptions that underpin my comments today and I want you be aware of these. First, our interest in the behaviour and well being of parents is driven primarily by our focus on the well being and development of children. The child is our starting point—parenting skill development programs attempt to develop and enhance the quality and style of nurturing that children receive from their parents. Second, our interest is not primarily one of parent advocacy—except that we strongly advocate the right of all parents to have access to support that is based on best practice and evidence based interventions. Third, the context I am coming from here is primarily a clinical one—it is about how a practitioner can best work with a family who has come to the attention of the service system and who is experiencing challenges in adequately meeting the needs of their children.

Like our previous speakers, I have decided to examine the three questions that are guiding our general discussion here today:

1. What do we know about providing effective interventions to families where one or more parents has a learning disability? Here I will try to address the issue of what is best practice, and how good is our 'best practice';
2. How are we doing now as a service system? This is the question of whether we are implementing best practice and what might be some of the potential barriers to implementing best practice with this group;
3. Where to from here?

Why focus on parenting?

Before I can begin to answer these questions we need to spend a small amount of time looking at why it is important to focus on parenting. It is very important to ensure that all

parents in our community are properly supported in the challenging task of raising their children. This can involve equipping parents to create optimal environments for children to grow and develop. There are three very compelling reasons for doing this:

1. Many years of developmental and intervention research has demonstrated that what parents do—especially what they do in the many thousands of daily interactions with their children—does matter in relation to short and long term outcomes for children;
2. There is now plentiful evidence of a link between parenting and family factors and the development of mental health problems in children, particularly serious behaviour problems (Sanders, 2002). Parenting factors are among the strongest predictors of a range of psychosocial and developmental problems in children; and
3. There is now abundant evidence from intervention research that parent focused interventions can produce strong and long lasting positive effects in relation to child development and behaviour (for a discussion see Shonkoff & Phillips, 2000). This evidence comes from a diverse range of areas, but is particularly strong in relation to the treatment of childhood behavioural problems and child abuse.

The question then that I am attempting to address here today is how do we ensure that parents with learning difficulties are properly supported in the task of child rearing.

Parent focused interventions and parents with learning difficulties

Like all parents, some parents with learning difficulties appear to cope with the demands of parenting adequately, and some do not (Espe-Sherwindt & Crable, 1993). There is now substantial evidence that learning difficulties in a parent does not inevitably result in child neglect or abuse. As has been pointed out by previous speakers, there is no clear, linear relationship between parental competence and intelligence.

Despite this, research in Victoria and New South Wales has shown that parents with learning difficulties are disproportionately represented in the child protection system (McConnell, Llewellyn & Ferronato, 2000; Swain, Goodfellow, Lee, Cameron & Bennett, 2002). Why are parents with learning difficulties so over-represented?

The reasons for this are complex. But what is clear is that it is not simply a matter of the parents having learning difficulties. Reviews of the literature point to three possible factors:

1. The role of the families' living conditions and circumstances: like many other families that come to the attention of the protective service system, parents with learning difficulties often: (a) live in chaotic and impoverished social circumstances (poverty, unemployment, insufficient social supports); and (b) have personal histories characterised by a range of psychosocial problems—high levels of stress, maltreatment, depression and lack of opportunity to learn parenting skills in normal family life.
2. The role of prejudicial beliefs, perceptions, and expectations in the community: parents with learning difficulties are often subjected to attitudes and beliefs that impede the provision of effective supports. For example, assumptions of incompetence, inaccurate views based on stereotypes of people with disabilities, and lack of belief in the person's capacity to change and develop skills. Some more on this later.
3. The role of significant gaps in the support system, and the fact that the health, welfare and education systems in our country and our State are struggling to meet the specific needs of this group.

What do we know about providing effective interventions to families where one or more parents have learning difficulties?

Research has shown that when teaching methods are matched to their learning needs parents with learning difficulties can learn, retain, and generalise parenting skills taught to them. The evidence for this has been generated by a number of research groups across the world, including researchers in this country.

Research programs have demonstrated that skills in a range of parenting domains can be taught to parents.

- **Basic Infant and Child Care skills:** Maurice Feldman and colleagues have conducted a number of evaluations of programs designed to equip parents who have special learning needs with basic training in child-care skills. Using both single-subject and between group designs, these researchers have demonstrated that parents with learning difficulties increased their skill levels as a result of the interventions in skills such as newborn care, feeding, bathing, and cleanliness (Feldman & Case, 1999).

- Parent-child interaction: Again, Feldman and colleagues have conducted a series of evaluations of programs designed to enhance the quality of parent-child interaction. They have successfully taught parents with learning difficulties a range of interactional skills including imitation, praise, physical affection and play (Feldman, Case, Rincover, Towns & Betel, 1989).
- Health, home safety, and emergencies: Using a randomised controlled trial, Llewellyn and colleagues recently evaluated the efficacy of a home-based intervention targeting parents with learning difficulties. Skills training focused on health and safety including understanding sickness and health, fire safety, safe use of electricity, cooking safety, poisons and general home safety (Llewellyn, McConnell, Honey, Mayes & Russo, in press).
- Child behaviour management: This is the area with the least amount of attention. However a series of single-subject research designs, conducted by different researchers and clinicians, have taught parents to:
 - correctly *identify* appropriate and effective parenting responses to their children's behaviour (Bakken, Miltenberger & Schauss, 1993); and how to
 - increase positive interactions in the home (Tymchuk & Andron, 1992)
- Problem solving and decision making: Again, this is an area with little research. Tymchuk and colleagues assessed the effectiveness of training in how to identify and apply decision-making steps. Results showed that problem solving and decision making could be significantly improved by training (Tymchuk, Andron & Rahbar, 1988).
What can we learn from this research in relation to best practice parent focused intervention for families where a parent has a learning difficulty? I would like to make some brief comments on three main areas: Engagement, assessment and intervention strategies.

Engagement

Practitioner's working with parents who have learning difficulties almost always begin with a series of hurdles related to parent engagement.

First, they often have to counter the negative effects of system coercion. Many of our clients are compelled to attend for treatment or assistance by external bodies including courts or the protective service system.

Second, many of these parents have been subjected to frequent criticism and demands for change. Many struggle with a strong subjective sense of incompetence and have often been confronted with the view that they are not up to the task of parenting. Clearly, it can be clinically challenging to help activate a demoralised person into a genuine change process. Third, in addition to issues in relation to child rearing, many of these families experience multiple problems and live in chaotic and unstable environments. It can be difficult for the practitioner to achieve and maintain a focus for intervention when there are so many crises and interruptions to the attention and flow of a program. Fourth, it can also be difficult to get parents with learning difficulties to articulate goals and aspirations for the future. Envisaging a different future and exploring the repercussions of change is a taxing cognitive task and not always easy for our clients.

It is easy to get frustrated at the slowness of learning and the forgetting. Our frustration at the slowness of change can evolve into a client blaming scenario, where the responsibility for lack of change is laid at the feet of the client rather than seen as a problem in the therapeutic process. It is also easy to interpret lack of progress as lack of motivation on the behalf of the client, when in fact the lack of action and change may be more associated with a lack of understanding on the client's part and a lack of opportunity to learn the skill or new behaviour in a way that fits best with the client's learning style.

Researchers and clinicians who are working with multi-stressed families are now stressing the need for practitioners to:

1. Establish a genuinely collaborative relationship, that involves the client as an active partner, and that uses what the client wants to work on as its starting point (Madsen, 1999).
2. Focus attention on client strengths—and the clearly stated goal of strengthening and enhancing the family unit.
3. Pay greater attention to establishing the motivational conditions required to achieve personally meaningful goals. In fact, it needs to be recognised that creating the motivational conditions required for change is fundamentally the job of the practitioner (see Kanfer & Schefft, 1988). Practitioners should be aware that subtle or not so subtle forms of coercion can achieve compliance, but rarely genuine change. In particular,

substantial time needs to be invested in eliciting, clarifying and building commitment to personal goals—goals related to improving the parent’s life and circumstances; goals related to the care and nurturing of the child; and goals related to the family unit.

Assessment

The issue of assessment is a thorny one: not least because there is a lack of a generally agreed definition of what adequate or ‘good enough’ parenting actually is. Sure, it is relatively easy to identify extreme examples of poor parenting behaviour, and examples of positive parenting behaviours. But essentially we do not have an empirically based process for determining whether the parenting provided for a child is adequate or inadequate—nor do I think we will ever have one, nor do I think that such a ‘tool’ if it were to be invented would be a good thing. What constitutes ‘good enough parenting’ is likely to remain a constantly evolving social construct that will not lend itself to reliable measurement.

The problem to be confronted though is this: in the absence of an empirically based approach, workers can end up relying on clinical judgements, and gut feelings, both of which are clearly subject to the risks of bias. And in relation to parents with a disability, there appears to be evidence that personal assumptions and beliefs about the nature of disability can and do colour the way situations are interpreted and reported.

Understandably, many writers in this area have urged practitioners who are routinely called upon to report on parenting capacity to courts or other statutory services to exercise extreme caution because of the limitations to our current assessment technologies and because of the potential for bias (Azar et al., 1998). Therefore attention has increasingly focused on developing assessment processes that inform and lead to effective interventions.

We believe that it is generally unhelpful in a clinical context to generalise from a class of person to the person who is the focus of attention. That is, knowing what diagnosis has been given to a person does not tell us a lot about what they actually do as a parent. For

example, the least useful bit of information in finding out how a specific individual actually parents—how they interact and care for their child on a daily basis—is an IQ score. Close on the heels of this kind of information is personality testing and measures of theoretical parenting constructs such as hostility, warmth, authoritarian, authoritative etc (see Green & Killili, 1998 for further discussion on these points). Even useful constructs like ‘attachment’ are notoriously difficult to operationalise and are particularly subject to cultural bias in interpreting ‘attachment’ behaviours (Azar, 1998).

Instead, we advocate what Sandy Azar, Alexander Tymchuk and others have termed a ‘functional contextual’ approach to assessment—moving the focus from what people are (how they are labelled) to the collection of information about what they actually do (See Azar, Lauretti & Loding, 1998; Tymchuk, 1998). This of course is the starting point for effective parent focused interventions.

A functional contextual approach begins with an attempt to understand the unique situation that is created when a particular individual, is parenting an individual child in a specific psychological and environmental context. Assessment then becomes a process of illuminating the functional relationships between a person’s behaviour and their environment, and the kinds of environmental influences that determine the nature, frequency and quality of those responses.

In relation to improving assessment practices, there have been calls for:

1. A greater emphasis on the use of assessment tools that directly measure aspects of parenting behaviour and have sound psychometric properties in order to reduce the impact of worker bias and assumptions.
2. A greater emphasis on the use of direct observation of parental behaviour in the person’s environment—and the discipline of describing rather than interpreting behaviour.
3. Increased use of task analysis approaches: this involves breaking down complex child care and interaction tasks into a series of steps that are ordered sequentially. Such fine grained analysis produces a detailed understanding of existing parental competencies and areas that might be strengthened or developed.

Intervention strategies

The most effective parent focused interventions have been based on social learning principles. They have been characterised by rigorous and systematic attention to the process of helping individuals acquire, maintain and generalise observable parenting skills. Here I am referring to instructional strategies developed and honed by the applied behaviour analysis movement—task analysis, positive reinforcement, modelling, prompting, shaping, behavioural rehearsal, feedback, practice—strategies which incidentally have in and of themselves made a significant contribution to revolutionising the lives of people with a disability.

A number of researchers including Feldman (1994; 1998), Jones (1996), and Llewellyn (1997) have identified some critical elements in effective parenting skill development programs designed for this group specifically:

1. Teaching and learning needs to take place in the setting in which the skills are needed. It is important that the parent has an opportunity to learn and practices the skills in the environments where they need to be used.
2. The focus needs to be on acquiring and performing actual skills. Increasing a parent's knowledge or understanding of what to do may influence their verbal behaviour, but research shows us that this does not lead necessarily to the performance of the skills. Shaping up actual performance of parenting skills is necessary for these skills to be acquired.
3. Instructional strategies: to reiterate—the most effective teaching strategies involve intensive behavioural instruction including: task analysis, clear instructions, modelling, concrete examples from the parents everyday life, immediate feedback, prompting, lots and lots of practice, and lots and lots of positive reinforcement.
4. There is also evidence that a range of instructional materials/and teaching aides (pictorial manuals, audio tape, video etc) hold promise in facilitating learning when paired with parent educator support.
5. Ensure the program is flexible, long-term, and actively plans the generalisation and maintenance of skills (working in the home, using everyday interactions as teaching opportunities, and teaching multiple examples of the same skill or concept).

The need to embed parent training in broader supportive contextual interventions

Even programs that are based on sound learning principles and are well planned and rigorously implemented have been found to have limitations. These limitations refer specifically to problems in ensuring the maintenance and generalisation of new skills and in equipping families to deal with novel, unexpected events and circumstances (very much part of the parent's life).

Additionally, families who are coming into contact with the welfare system and have a parent with learning difficulties have very complex needs and multiple problems. The gains of parent skills programs can be short lived when other major social and personal problems go unaddressed.

There is now a strong body of research evidence that shows the benefits of providing parent skills training in conjunction with other family-focused supports. These *supportive contextual interventions* aim to assist parents in overcoming obstacles to effective parenting (depression, poverty, high stress levels and social isolation). Examples include teaching various life skills, budgeting, stress management, problem solving, relationship skills and so on. In particular, researchers are consistently suggesting that, in addition to parent skills training, practitioners should devise strategies that promote the development, access, and use of community-based support networks by parents with learning difficulties.

The simple provision of social support is not sufficient to enable a parent to demonstrate a skill, if that skill is not currently in their repertoire. On the other hand, providing social and personal support may be one of the most effective ways of ensuring that parents are given the opportunities to develop a skill or competency, and that once acquired — such skills will be used and supported and maintained.

How are we doing now as a service system?

Of course health, welfare, and education systems attempt to meet the needs of parents with learning difficulties on a daily basis. They often do this in a context of high caseloads, low level resources and limited time. In Victoria, there have also been a number of important and valuable specialist and focused initiatives in this area.

1. In 1998/99 the Department of Human Services published a series of resources on the topic. These included:

- Parents with an Intellectual Disability: A workers manual
- Parents with Intellectual Disability and Older Children: Strategies for support workers
- Out of the Mainstream: A parenting group for parents with an intellectual disability and their children

2. A number of support groups for parents with learning difficulties have been established and continue to be operational. These include Out of the mainstream (Northern metropolitan region) and Parents are We (Southern metropolitan region). These are small facilitated peer support groups, locally based. The focus and content of the groups is driven by the participating parents.

3. There are also examples of in-home parenting services established to meet the needs of these clients. The Family Outreach Support Service (Northern Region) and Specialist in-home parenting service (Southern Region). These two programs provide a home based service which deliver family focused support, education and skills development training to parents with an intellectual disability.

4. Maternity Care: the WIN Clinic (Women's Individual Needs') at the Royal Children's Hospital aims to improve mainstream maternity services by providing an enhanced range of care options to women with complex needs, including intellectual disability.

5. IDEAS program (Intellectual Disability Parenting Education and Support): The Victorian Parenting Centre is currently involved in the development, implementation and evaluation of the Parenting IDEAs. This is an intensive, individualised home-based

parenting program that aims to strengthen and improve parenting skills. The focus includes:

- developing their skills in particular areas of child care, including toilet training, food preparation and handling, meal time issues, shopping, nutrition, bathing, bedtime and sleeping, personal hygiene, health monitoring, emergency management, and safety;
- initiating and maintaining positive interactions with their young children; and
 - using positive-based non-corporal strategies to increase child appropriate behaviour and decrease difficult behaviour.

The long-term goal of Parenting IDEAS is that the content area and instructional strategies could be incorporated into an existing generic parenting service.

Assessment of the status quo against best practice

The specialist programs and services that I have referred to, have not as yet been systematically evaluated — they appear to be meeting an important need — but from a scientific perspective we really still don't know how effective they are in relation to helping parents acquire the skills they need to become independent. There is an urgent need to resource these programs so that thorough evaluation can be undertaken and important learning's, approaches and skills documented, preserved and disseminated.

There is no evidence that parents with learning difficulties benefit particularly from participation in mainstream parenting education programs—especially when such programs are essentially verbally based. Additionally, there is ample anecdotal evidence that generalist health and welfare services are struggling to meet the needs of parents with learning difficulties.

We simply do not know whether current practice across the full range of service settings reflects best practice in relation to engagement, assessment and intervention in the way I described earlier. However, we do know that many practitioners feel poorly prepared to meet the needs of this group. Australian studies in the late 90s conducted by Llewellyn and colleagues show that many service providers report that they lack the necessary skills, training and confidence to work effectively with these parents (Llewellyn, 1990). Feldman

and others (1989) found that workers often relied on popular but ineffective teaching strategies, including verbal instruction and brief demonstration, when teaching parents with learning difficulties. These researchers also pointed out a tendency for workers to resort to less effective intervention strategies—explanation, reasoning, brief demonstrations—when confronting challenging clinical situations.

What are the barriers to the adoption of effective practice?

Many barriers to the adoption of evidence based practice are systemic and structural. The problems can be found in the way services are structured and the way they relate to each other. I want to look at these briefly and touch on two other potential barriers to implementation of best practice: practitioner attitudes and training.

Structural barriers

A series of brainstorm sessions with service providers in three DHS regions was conducted recently by the Victorian Parenting Centre. Participants were asked to identify the barriers they experienced in attempting to do their jobs effectively. The following is a summary the kinds of issues they raised:

- too few services
- many services unable to provide interventions that are intensive enough or long enough
- generic and universal services find it difficult to adapt their approach
- reactivity of services (rather than pro-active) –orientated towards crisis rather than longer term skill building
- problems with physical access to services e.g., transport
- high turnover of staff
- patchy communication between services
- over-serviced families e.g., too many people involved at once
- limited flexibility
 - times of day
 - more intensive for a period – then less intensive
 - allowing families to enter then re-enter services
 - meeting number targets

- continuity of care across services

Clearly, if services are to be able to respond adequately to the needs of parents with learning difficulties they need the staffing, time and flexibility to do so.

Attitudes of service providers

As mentioned earlier, our beliefs about the nature of disability and the learning process influence the way we work with families. It is easy to fall into a focus on deficits at the expense of recognising strengths and competencies. An assumption that a client does not have the capacity to learn tends to lead to the provision of fewer opportunities to participate in activities that foster the development of competence. A deprivation in learning opportunities can result in a person becoming more incompetent over time. This then justifies and reinforces continued pessimism about the parent's potential for development, and so the cycle goes on.

Conversely, a perception of personal competence will directly affect the nature of the supports that are provided. Once we recognise strengths we develop positive expectations about the parents' ability to learn and do new things. Positive expectations lead to the provision of opportunities to develop. These opportunities, in turn, provide positive and valued experiences for the parent and those around them. As a result, the parent develops additional competencies that, in turn, justify and reinforce our original view—that is, the individual can learn (Gold, 1980).

To be successful in this area, practitioners have to develop an intense belief in the fundamental competence of all people, and optimism that change is possible, if only the right set of conditions is reached. Where failure is experienced, it is attributed to the limitations of our helping technologies rather than to something innately unchangeable in our client.

Where to from here

Many challenges remain. In particular, further intervention research needs to be conducted to address the significant gaps in our knowledge; especially in relation too:

- content areas such as child behaviour management and problem solving

- maintenance and generalisation of gains during intervention
- the potential use of instructional aides and self-learning materials

The gap between what works best and its application in actual practice needs to be bridged. Attempts to date have not been sufficiently systematic or supported. The result is practitioners on the ground feeling ill-prepared, lacking in time and resources, and limited by programs that allow only brief and inadequate services for people with learning difficulties.

Issues related to staff training, case management and supervision also need to be addressed. It is now commonly accepted that professional skills, experience, and adequate supervision are major determinants in the successful provision of supports and interventions. Similarly, planned and coordinated services can only enhance positive outcomes for families where there is a parent with learning difficulties. Absence of these features throughout the service system work against practitioners' best attempts to make a difference in the lives of parents with learning difficulties.

Take home messages

I would like to finish by attempting to briefly summarise the key take home messages from this talk. There are six:

1. Starting from the wellbeing of a particular at risk child, the most powerful intervention is one that strengthens and improves the quality of the parent-child relationship.
2. Parenting interventions have demonstrated efficacy with parents who have learning difficulties across a range of parenting domains.
3. The most effective interventions for parents utilise teaching technologies that match the client's specific learning needs.
4. The most effective parenting interventions are embedded in a broader eco-behavioural perspective. It is necessary to also pay attention to the individual's broader physical, social and psychological environment, if parents are to acquire and maintain new skills over time.
5. Our most effective interventions are not necessarily those that are being used in the community.

6. There is a pressing need for more research and a more systematic approach to evaluating programs developed for parents who have learning difficulties.

Finally, the field of parenting education and support should view the issue of parenting with learning difficulties as much more than simply a side issue or a specialist issue. In fact, this issue is an important testing and proving ground for the parent education field: it challenges us to strive towards greater sophistication, greater understanding, and improvements in our content and in our processes.

Such gains if we achieve them have the potential to benefit all the parents and families that we serve—not just those that have been identified as having a disability. If we can get it right for this group, chances are that it will right for everyone.

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Description of panel sessions

Forum participants were allocated to one of three panel sessions, each focusing on one theme. There were three speakers for each panel. The sessions began with the speakers briefly responding to a statement. This was followed by a response from the other speakers, and a broader group discussion.

Panel session 1: Where are we at?

Statement: As a society we do not accept that parents with special learning needs are capable of being good parents

In panel session one the main focus of the discussion was on the failure of our society to accept people with disabilities as citizens who have sexual relationships and can become parents. The focus on individuals in our community serves to further isolate and marginalise people with a disability. Finally, as a society, we are not clear on what it means to be an effective parent and there needs to be greater focus on outcomes of good parenting (ie what we expect in the child as an outcome of good parenting).

Panel session 2: What are we doing?

Statement: The current support and service system does not effectively meet the needs of families where the parent has a special learning need.

In panel session two there was discussion about the current service system response and the need for greater collaboration and co-ordination of services. There was discussion of the need for both specialist and mainstream service responses to the issues. The need to evaluate existing practice and provide appropriate training to staff was also highlighted. The need to raise community awareness and promote greater inclusion of parents with special learning needs was emphasised.

Panel Session 3: How are we doing it?

Statement: Our current practice does not effectively meet the needs of families where the parent has a special learning need.

In panel session three there was an acknowledgment of factors having a great impact upon the capacity to parent such as being isolated, unsupported, sole parents on a low income. Particular attention was drawn to the problems facing the Children’s Court in seeking to balance the rights of the child with those of the parent. Problems were identified with both the methods currently used to assess these parents and the lack of flexible service intervention, which seeks to accommodate different learning styles.

Themes raised in the panel sessions and workshops

From these discussions key themes, actions and tasks were identified by forum participants. The following is a summary of these.

Theme 1: Understanding of what constitutes “adequate” parenting.

In sessions one and two there was significant discussion about the judgements, values, and perceptions that heavily influence the views of what it is to be a good parent. It was suggested that any assessment of parenting needs to be grounded in the outcomes we expect in children. However, because we are unclear on outcomes we expect in the child there is greater scope to be critical of parenting styles and approaches that may still achieve positive outcomes for children.

Actions	Tasks
1.Gather knowledge of child development and parenting practices	1.1. Form a diverse working group to look at gathering knowledge of parenting practices. 1.3. Form partnerships

2. Gather and document previous work in the area	2.1. Undertake a scoping project of approaches to the support of parents with special learning needs.
3. Define adequate/competent parenting	3.1. Consult with the children's court? 3.2. Identify indicators of effective parenting, with a clear focus on outcomes for the child, so that different parenting styles and approaches can be accommodated. 3.3. This also needs to take account of the different factors, which affect the context of parenting.
4. Evaluate model	4.1. These indicators of effective parenting need to be evaluated.
5. Listening to parents	5.1. For example through wider distribution of the video 5.2. Workers to ask parents what they are doing, listen to parents

Theme 2: Perceptions of disability and the context of parenting

Session one highlighted the problems, which stem from people with disabilities not being considered citizens, and not seeing them as forming relationships or indeed becoming parents. Too often the issue of parenting and disability is considered to be a disability issue when it needs to be seen as a societal issue. In sessions one and three there was a recognition that any attempts to support families needs to consider other important factors that can affect the person's capacity to parent such as poverty, poor education, housing, living in remote areas, and ethnic background. Failure to consider the impact of these factors can lead to undue emphasis on disability and ineffective support of these families.

Actions	Tasks
1. Raising awareness in	1.1 Consult with and provide information to

<p>the community – to develop accurate perceptions of families where parent(s) have special learning needs</p>	<p>culturally diverse groups and organisations</p> <p>1.2 Conduct media campaign on valuing difference, which highlights positive experiences of parenting and disability.</p> <p>1.3 Encourage parent to parent connections (to communicate positive experiences regarding informal and formal supports)</p> <p>1.4 Agencies' provide community education (e.g. information and talks to HACC, schools etc)</p>
<p>2. Reducing social isolation</p>	<p>2.1 Conduct research on successful intervention (i.e. where community inclusion has occurred and is successful and identify factors related to engagement and success)</p> <p>2.2 Conduct research on families who are managing well without intensive services intervention. Identify what works well.</p> <p>2.3. Parenting groups play a key role in the support of parents. Need to offer these groups and evaluate their impact upon parenting. The approach of these groups should be no different for parents with special learning needs.</p> <p>2.4. Disability services actively involved in neighbourhood renewal</p>
<p>3. Identifying what parents with ID, who do not come into contact with the system, are doing well.</p>	<p>3.1 Conduct research into factors related to parents who are doing well</p> <p>3.3 Consult with research groups to find a sensitive way of involving resilient families with an ID in research</p>

Theme 3: Access and inclusion, the mainstream vs. specialist debate

In all three sessions the issue of making parenting support accessible to all was discussed, with the suggestion that if it was made accessible to parents with special learning needs then it is more likely to be accessible to other vulnerable and disadvantaged families. In addition to making mainstream parenting support agencies more accessible to these families, the need for specialist parent support agencies in the disability area was acknowledged. These specialist agencies would have a role in resourcing the mainstream parent support agencies as well as providing support to families directly where this was considered necessary.

Actions	Tasks
1. Early intervention/ prevention	1.1 Increase access to early education and have a pre-natal focus within the mainstream system
2. Response needs to be timely and locally based.	2.1 Have clearly defined pathways to access these services.
3. Stop "buck-passing" or "hand-balling" between systems	3.1 Allocate a case manager to co-ordinate services.
4. Specialist "teams" within disability services and child protection, etc.	4.1 Advocate for specialist teams within the systems. 4.2 Teams to provide early intervention and education
5. Integration into mainstream services	5.1 Pre-natal care options to be available to parents with ID in the mainstream system 5.2 Access to respite services that are currently available to parents with a child who has a disability.
6. Reduce stigma associated with being involved with services	6.1 Reduce focus on assessment as necessary prior to entry to a service 6.2 Increase resources to services so they can provide a service to specialist populations within

	a generalist service.
7.Support for people with disabilities in dealing with relationship issues	7.1 Provide greater support to people with disabilities through information and counselling on relationship issues.

Theme: 4 Need for greater collaboration between and integration of services

The single focused nature of service provision does not address the complexity of the issues confronting parents. This often means that either the support is inadequate or that there are too many services involved with the families. There was recognition that the service response, which can focus on the child rather than seeking to assess the interrelationship with parents, consequently overlooks the needs of the individual family unit and their unique circumstances. This then has implications for the effectiveness of the intervention and support proposed. This was seen as creating its own series of problems such as confusion for the parents as a result of conflicting advice. There is a need to shift the focus of the system from one that concentrates solely on child protection to one of family support, and that this support role should occur across the health, education and welfare systems.

Actions	Tasks
1. Collaboration between services in order to more effectively address the complexity of the issues.	1.1 Training for disability workers in notifying/reporting 1.2 Training for child protection workers in disability 1.3 Formal training (<i>not sure what this means</i>) 1.4 More forums like this to increase workers awareness of the issues across services 1.5 Engage the two divisions via the Children & Family Framework that is currently being enacted within DHS 1.6 Approach the Departmental Heads to

	advocate for the engagement of the two divisions.
2. Education of all staff in DHS, other government and non-government agencies about policies, protocols and principles of service delivery to parents with special learning needs	<p>2.1.Share existing expertise via</p> <ul style="list-style-type: none"> • coaching /co-working with other agencies / divisions • worker 'swaps' between agencies / divisions • establishing / re-establishing networks across regions <p>2.2.Set expectations of the above within policy frameworks and staff work plans</p>
3. Remove constraints to flexible service delivery	<p>3.1 Establish (or review and re-establish) protocols for working across services</p> <p>3.2 Allow access to intensive family support services for families who need such resources but are not protective service referrals.</p>
4. Equip parents with skills to manage emotions	<p>4.1.Teach parents with an intellectual disability anger management and coping skills.</p> <p>4.2. Have specialist services teach these skills</p> <p>4.3. Have mainstream services for emotional management skilled in working with parents with an ID.</p>
5. Gain effective case management to coordinate multiple services.	<p>5.1. Have better coordination between courts, protective services and case management to better address families involved with multiple services.</p> <p>5.2. Have better allocation of appropriate services</p>
6. Magistrates need to have a better understanding of the best	<p>6.1. Have better communication between magistrates and the services likely to be involved.</p>

approach for parents and services.	
7. Protective workers to be motivated to attend workshops on disability	7.1. Provide disability training for child protection and parent support agencies.

Theme: 5 Staff Training and Support

Staff in a range of areas need to receive appropriate training and support in how to work effectively with families where the parent has a disability. This requires the development, documentation and evaluation of best practice in the field.

Actions	Tasks
1. Skill up the whole workforce in working with people with an intellectual disability	1.1. Need modules on working with parents with a disability in various professional training programs.
2. Make positions within services more attractive in terms of conditions of employment	2.1. Wages and salaries for works need to reflect the skills and expertise required of workers.
3. Develop a team approach within an organisation to utilise everyone's skills	3.1. In house training to share skills already in an organisation or team. 3.2. Have very good supervision practices 3.3. Better communication between staff and organisations. 3.4. Organise more consults with other organisations.
4. Other sectors such as	

<p>family support need to work more collaboratively with Disability Services</p>	
<p>5. Increase use of adult learning techniques</p>	
<p>6. Better training for people who are involved in training other professionals to create a life cycle?????? Also needs to be training of Judiciary and court staff on parents with special learning needs.</p>	<p>6.1. "Train the trainer" training for those already in the field to improve passing on of skills and information.</p> <p>6.2. Teach trainers about the meta-skills e.g., the process as well as the context.</p> <p>6.3. Contact courses supplying workers in the field to include best practice in their training</p>

Theme 6: Developing best practice in working with families

Current approaches to assessing and supporting families are often driven by assumptions and a narrow focus upon diagnostic categories. The existing risk assessments are not a reliable predictor of abuse/neglect. Indeed the risk framework actually states that “ID is not a significant risk factor to the child”. Need to move to a strength-based approach, which builds on existing skills and knowledge and takes account of the socio-economic context in which the parenting occurs.

Actions	Tasks
1. Improved methods of assessment	1.1 Move away from current diagnostic and risk based assessments to ones that use direct observation and task analysis. This approach needs to be functionally based, looking at knowledge, skills and learning ability. Assessment needs to be sensitive to cultural and other environmental factors
2. Improved methods of intervention	2.1 Develop and evaluate a flexible practitioner approach which seeks to meet the learning style of the parent. 2.2 Responsibility should be on the practitioner to enable parents to acquire parenting skills. 2.3 Utilise adult learning techniques, which promote adaptive strategies. 2.4 Help parents to assist their children to develop skills to be able to survive later in life. 2.5 The support of parents should also consider the importance of insight, judgement and foresight in being an effective parent.

	<p>2.6 Take account of other factors, which affect families such as socio-economic factors, culture and ethnicity.</p> <p>2.7 Provide different support for families where the children are adolescents where required.</p> <p>2.8 Provide ongoing support rather than time limited service as the demands change over time for the parent.</p> <p>2.9 Offer support to adolescents who may be taking responsibility for the parent.</p>
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Theme 7: Tension between rights and relationships

The focus on the rights of the child or indeed of the parent often does not effectively consider the importance of family relationships. In the child protection context it was acknowledged that the adversarial process promotes an approach that seeks to promote the rights of the child or the parent, sometimes at the cost of the family.

Actions	Tasks
1. Need to consider alternatives to adversarial process.	1.1. Explore less adversarial approaches to address child protection issues, which may require legislative change.
2. Enhance connections between Disability and Child Protection systems.	2.1 C.P. to work with professionals in a collaborative way, so that professionals do not just see C.P. as source for notification.
3. Establish appropriate	3.1 Review current methods of assessment such

methods of assessment	as cognitive and risk assessments as not giving useful information to the court about capacity to parent.
4. Improve training of workers (Disability, Child Protection, G.P's)	4.1 Include GPs in training on making a notification to C.P.